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ABSTRACT

This manual is intended to accompany technical assistance efforts aimed at improving selected states' home health care programs for children with chronic illness and severe disability. Summary descriptions of funding sources are presented, including purpose, eligibility guidelines, and services covered, as well as additional information as warranted. The first section of the manual describes funding streams available to states and applicable to home care support, including: medical care (six); income support (two); social services (eight); educational services (four); transportation (three); and housing (seven). The second section reviews different strategies states have used to enlist insurance companies in a public partnership supporting home care. Appendixes list legislative acts and authorization for programs and provide a chart of federal participation rate for Medicaid programs by state. Contains 45 references. (PB)

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Financing Options for Home Care for Children with Chronic Illness and Severe Disability

Technical Assistance Manual

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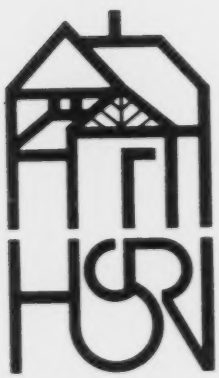

HUMAN SERVICES RESEARCH INSTITUTE

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FINANCING OPTIONS FOR HOME CARE FOR CHILDREN WITH CHRONIC ILLNESS AND SEVERE DISABILITY

TECHNICAL ASSISTANCE MANUAL

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In addition, the following sources were heavily drawn upon in the preparation of this document. (Full citations of the works are listed in the Reference section).

Fox Health Policy Consultants:

A preliminary analysis of options to improve health insurance coverage for chronically ill and disabled children (Report). September 1984.

Documentation of cost effectiveness under the 2176 Waiver Program for Home and Community Based Services (Memorandum) April 1985.

Presentation on the policy implications of various catastrophic health expense program options for children (Presentation). July, 1987.

Legislative amendments affecting access to care by children and pregnant women (Memorandum). March 88, 1987.

Task Force on Technology Dependent Children. *Fostering home and community-based care for technology dependent children.* (Vol. II). 1988.

The opinions expressed herein are solely those of the authors and should not be construed otherwise.

INTRODUCTION

Under the auspices of the National Institute on Disability and Rehabilitation Research, the Human Services Research Institute was awarded a grant (Contract #G0086C3523) to examine financing models for supporting children with severe disabilities and chronic illness so that they may live at home. One activity of the project entails the provision of technical assistance to selected states to facilitate the expansion of home health care for children. This manual is prepared to accompany these technical assistance efforts as well as to provide information to families and professionals alike regarding funding possibilities.

The information presented here provides a broad overview of the variety of programs, funding streams, and financing options that can be employed by state planners and others interested in expanding opportunities for home care.

Summary descriptions of funding sources are presented that alternatively or in combination can be used to support various facets of home care such as medical and educational needs. The sources described may apply to children with chronic illness or severe disability who live with their parents or in a home with other caretakers. The first section of the manual describes federal funding streams that are available to states that may be used to support home care. The second section reviews different strategies that states have used to enlist insurance companies in a public/private partnership to support home care.

The summary of each funding source provides the following information: 1) purpose; 2) eligibility rules or practices; and 3) the services covered. Additional information is presented where warranted.

PART ONE: PUBLIC OPTIONS

This section of the manual reviews the purpose, eligibility requirements and services covered by federally financed programs that are relevant to children with chronic illness or disabilities who are living with their families or in other home settings. The basis for each program is presented along with pertinent modifications to the original federal authorizing legislation.

MEDICAL CARE

MEDICAID: MEDICAL ASSISTANCE PROGRAM

Purpose

This program (often referred to as "Title 19" because of its authorizing legislation) provides federal financial assistance to states for medical services furnished on behalf of public assistance recipients and, in some states, on behalf of other medically needy persons who, except for income and resources, would be eligible for cash assistance. The federal matching rate varies by state and is determined under a complex formula geared to state per capita personal income. The federal share of program costs ranges from 50% to 80% (new matching rates for federal FY 1989-90 were issued by HCFA on October 27, 1988). The Medicaid program is administered by a state's "single state agency," and the agency must operate under a Medicaid state plan approved by the Secretary of the Department of Health and Human Services and comply with all federal regulations governing aid and medical assistance to the needy.

Eligibility

There are numerous categories of persons who are eligible for Medicaid. Federal law mandates that states must serve some categories of persons. Other categories of persons are eligible for Medicaid at state option and if they are listed in the state Medicaid plan. In some cases, if a state opts to include certain optional categories of persons in their Medicaid plan there are federal requirements that restrict the eligibility of those groups. Overall, the federal Medicaid statute encompasses a wide-range of eligibility options aimed at the extension of Medicaid services to children with severe disabilities who are members of low-income households or who have had financial deeming requirements waivered. Careful review of each state's Medicaid state plan is necessary to determine the range of eligible groups that are covered in a particular state and, consequently, the role Medicaid benefits might play in meeting the needs of such children.

The following pages describe the mandatory and optional eligibility groups.

This section was prepared with the assistance of Kathleen Blume of the Health Care Financing Administration; Gary Smith of NASMRPD; and Harriet Fox of Fox Health Policy Consultants

MANDATORY COVERAGE

AFDC Recipients

All persons who are recipients of payments under the Aid to Families with Dependent Children (AFDC) program are automatically eligible for Medicaid benefits (referred to as "categorically" eligible). Generally, the regular AFDC cash assistance program extends eligibility to children under age 18 (or 19 at state option) "where the child is deprived of the support of at least one parent (i.e., at least one parent is dead, disabled, continually absent from the house, or, in some states unemployed)" (Congressional Research Service, 1988) and who have caretakers with very low income. Family composition and financial eligibility standards for AFDC payments vary from state-to-state.

Adopted or foster care children receiving cash assistance under Title IV-E of the Social Security Act are considered to be AFDC recipients for purposes of the Medicaid program and are eligible for benefits.

"Qualified" Pregnant Women and Children

Pregnant women and children up to age 7 (or age 8 at state option) who meet the financial requirements of the state AFDC plan (or would be eligible for AFDC if the state AFDC plan included an unemployed parent program) are required to be covered by the state Medicaid plan. These groups, referred to as "qualified" eligibles, who meet AFDC financial requirements, do not have to meet family composition or "deprivation" requirements. At state OPTION, this coverage can be extended to children up to ages 18 through 21. (These recipients are referred to as Ribicoff children after the Senator who sponsored this legislation).

Poverty Related Pregnant Women and Children

Effective July 1989, all pregnant women and infants (up to age 1) whose family income is up to 100% of the federal poverty level ($9,690/year for a family of three in 1988) are eligible for benefits. Pregnant women are eligible only for pregnancy related Medicaid services and the infants are eligible for all Medicaid services available under the state plan. (This provision will be phased-in through July 1990).

SSI

In all but 13 states, all children (including adopted children) and other aged, blind, and persons with disabilities who receive cash payments under the federal Supplementary Security Income (SSI) program are also eligible for Medicaid. The remaining 13, states referred to as "209(b)" states, may choose to limit Medicaid eligibility to individuals who meet requirements that are more restrictive than those for SSI. The thirteen states are: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, Nebraska, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma, and Virginia.

When determining whether a child with handicaps is eligible to receive SSI, federal law requires that a certain portion of the family's income be "deemed" available to the child. This excludes many children in low to moderate income households from receiving SSI and Medicaid. However, if a child is institutionalized a full calendar month, the parent's income is not counted in determining SSI eligibility and resultant Medicaid eligibility. As a consequence, federal policies are often criticized as creating a bias toward out-of-home placement rather than supporting families.

OPTIONAL COVERAGE

Children Receiving State Supplements

States may provide supplemented payments to SSI recipients and persons with income in excess of SSI income standards. States have the option to extend Medicaid eligibility to children receiving the Supplemental payment. The income limits to receive a state supplemental payment vary by state.

Medically Needy

This refers to individuals and families who do not meet the financial eligibility limits for AFDC, SSI or state supplement, but who lack the resources to pay for their medical bills (usually because of inadequate private health insurance). In such instances, a individuals must "spend down" income for medical expenses until countable income falls to a level specified by the state. "Medically needy" individuals must satisfy special income and resource limits set in the state's Medicaid plan. Federal regulations require that a state set its medically needy income standards no higher than 133% of its AFDC payment standard. AFDC income limits and "medically needy" income limitations vary by state. In 1987, medically needy levels for a family of four varied from $267 in Tennessee to $1,009 in California. Thirty-six states currently operate medically needy programs. The numbers of persons served by a medically needy program vary widely and are dependent upon the level of the state AFDC payment (Fox & Yoshpe, 1987b).

Foster and Adoptive Children

This includes all foster care and adoptive children who have incomes and resources within certain prescribed limits and, who were placed by the state, but were not eligible for AFDC cash assistance prior to placement.

Pregnant Women and Children

This options includes all pregnant women and infants up to age one, whose family income is under a state established threshold that does not exceed 185% of the federal poverty level, and incrementally on an annual basis to children up to age 8 whose family income does not exceed 100% of the federal poverty level. Additionally, states may: omit testing for assets or resources (i.e. only test for income); use the more relaxed resource tests used by the SSI program; and/or disregard changes in income once a pregnant woman is determined to be eligible. Low income pregnant women and young children are not required to meet the family standards, other categorical criteria, or financial criteria of AFDC. Also, pregnant women and infants with family income above 150 percent (and up to 185%) of the poverty level, can at state option, be charged a monthly premium. This premium cannot exceed 10 percent of their gross income, less child care expense.

Waiver Recipients

States can opt to provide all Medicaid services to all persons with disabilities who meet the SSI disability criteria and who are receiving services through an approved home and community-based waiver or through a model waiver program.

Services covered

All states are required to provide the following Medicaid funded services:

* in and out-patient hospitalization;
* laboratory and X-ray;
* skilled nursing home for persons over age 21;
* home health services for persons over age 21;
* rural health clinic services;
* nurse midwife services in those states where midwifery is licensed or allowed by law;
* family planning;
* physician; and
* early and periodic screening, diagnosis and treatment (EPSDT) for children under age 21 (see below).

A state may also cover a wide variety of up to 32 optional service categories at its discretion, (e.g., preventive and rehabilitative services; home care or nursing care; home and community-based waivers; medical equipment and appliances; private duty nursing; home respiratory care services; and case management). States have wide latitude to limit the "frequency, scope, and duration" of Medicaid-covered services (e.g., by limiting the number of physician visits that will be reimbursed). Services under Medicaid except for home and community-based waivers and targeted case management must meet criteria of a "statewideness and comparability" (meaning that services must be equally available and of equal scope across all groups of Medicaid eligible). In most of these areas the state sets the standards for services. States also have broad flexibility in determining payment rates for covered services. Some states have elected to provide comprehensive and often unlimited coverage for all, or nearly all, of the federally allowed Medicaid services, while other states provide more limited benefits and may exclude extended home care, speech and occupational therapies. Moreover, a state can opt to exclude "medically needy" eligibles from optional Medicaid benefits. If a state offers home care they are required to provide nursing visits, medical equipment and supplies. Cost reimbursement methods (e.g., capitation through prepaid health plans) will affect the amount of reimbursement for care.

Of special interest is the fact that every state must provide EPSDT services to Medicaid eligible children under age 21. The Congressional Research Service (1988) describes this program.

> The EPSDT program is designed to assure the availability and accessibility of required health resources and to help eligible children use them effectively. Under EPSDT, states are required not only to finance services, but also to conduct outreach activities that link Medicaid-eligible children with providers. Each state's Medicaid program must (1) inform all eligible children about EPSDT services, (2) provide screening and diagnostic services, and (3) provide treatment to correct or ameliorate any discovered health problems.
>
> Each state must provide, at a minimum, the following EPSDT services: assessments of health, developmental, and nutritional status; unclothed physical examinations; immunizations appropriate for age and health history; appropriate vision, hearing, and dental services found necessary by the screening....
>
> States are permitted to provide services to children under EPSDT even if they are otherwise not available, or available on a limited basis, to other Medicaid beneficiaries (e.g., vision, hearing, and dental services that may not otherwise be available from that state's Medicaid program). (p. 322)

This enables a state to target an enriched array of services to children without risking financial exposure in the remainder of its program.

The Omnibus Reconciliation Act of 1986 (OBRA '86) also authorized state Medicaid coverage of at-home respiratory care services to ventilator-dependent individuals. Individuals must be medically dependent on a ventilator for life support at least six hours per day, and require inpatient respiratory care for which Medicaid would pay, if home respiratory care services were not available. The coverage permits a state to serve Medicaid eligible ventilator-dependent children at home without having to utilize a "2176" home and community based waiver (see the following).

The myriad of service options a state may elect under federal law as well as the special limitations a state may impose on covered services render it practically impossible to draw general conclusions about coverage, independent of each state's program. A careful review of a state Medicaid plan is required to determine the scope of service coverages and their potential applicability to furnishing home services to children with disabilities.

RECENT LEGISLATIVE CHANGES

Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA)

Purpose

TEFRA allows states to amend their Medicaid state plans to provide regular Medicaid services (but not non-medical support services) to *all* children with disabilities under age 19 living at home, who because of SSI income eligibility rules, (i.e., the undeeming of parental income) would be Medicaid eligible only if institutionalized. Relevant statutory provisions are contained in Section 1902(e)(3) of the Social Security Act. "TEFRA 134" coverage represented one outgrowth of the so-called "Katie Beckett" waiver program.

Eligibility

The individual must both meet the usual categorical criteria for disability under the SSI program and must require the level of care provided in a hospital, ICF, ICF/MR, or SNF. The state must ascertain for each child that home care is appropriate, and that the cost of this care does not exceed the cost for institutional care. Unlike the "waiver" program, this state option requires the state to cover *all* children with disabilities who meet the criteria on a statewide basis, whether or not they are institutionalized. The number of children that the amendment will actually affect depends on the restrictiveness of the state's interpretation of requirements of institutional care. States are free to develop their own implementing rules and to discontinue coverage for this group at any time.

Services Provided

Persons made eligible under the TEFRA state plan amendment are eligible for all Medicaid services provided by the state comprehensiveness plan. The amount and types of care available to the children depends on the of the state's Medicaid program and the willingness of states to expand Medicaid options. TEFRA does not provide authorization to furnish alternative or other optional Medicaid services. To offer such services, a state could seek approval for a Medicaid waiver (discussed later in this report). A Medicaid waiver can be operated in conjunction with a TEFRA amendment.

State Participation

As of 1988, only 22 states have amended their state Medicaid plans to add the TEFRA-134 coverage option. The reluctance of the majority of states to select this eligibility option reflects wariness concerning the costs of adding a new entitled service population (Allan Bergman, UCPA, personal communication).

Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA '85)

This act added a new section to the Social Security Act under which states were authorized to cover targeted case management as an optional service under their Medicaid plan. Case management is defined as services that will assist eligible individuals "in gaining access to needed medical, social, educational, and other services." Once such services are approved for coverage in a state's plan, federal financial participation in the cost of targeted case management services is made available at the state's regular federal assistance percentage. Case management can be targeted to specific populations without having to meet Medicaid "statewideness" or comparability provisions. The group may be identified by age, type or degree of disability, illness or condition "or other identifiable characteristic or combination thereof."

Medicare Catastrophic Coverage Act of 1988

The Congressional Research Service (1988) reports:

> The Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360) provides that state Medicaid plans which impose day limits on payments for inpatient hospital services must establish exceptions to those limits for medically necessary inpatient services for infants (up to age 1) in hospitals which serve a disproportionate share of low-income patients.... These changes have the practical effect of increasing compensation for the treatment of premature infants, infants with acquired immunodeficiency syndrome (AIDs), and other disabled infants in hospitals located in states with Medicaid programs that impose durational limits. (p. 330)

Omnibus Budget Reconciliation Act of 1988 (OBRA 1988)

As of January 1988, all residents of federally funded nursing homes who have mental retardation or developmental disabilities must be screened to determine if they require 24 hour nursing care. By 1990 alternative appropriate arrangements must be made for residents who do not require such care. States must also screen all new admissions by January 1989 and cannot admit an individual to a nursing home unless s/he has been determined to require the level of care provided by the nursing home (Bergman, 1988c).

MEDICAID: WAIVER PROGRAMS

HOME AND COMMUNITY BASED WAIVER

Purpose

This program (sometimes referred to as "2176 waivers" based on its authorizing statute) enables states to finance a variety of home and community based, non-medical support services not usually covered by Medicaid for recipients who would otherwise need more costly institutional care. Unlike service options available within the state Medicaid plan, coverage of home and community-based (HCB) services under the waiver requires the submission of a special application to HCFA. Once approved, waivers are effective for a three year period and can be renewed for a five year period. In its application, a state must designate which types of services it wishes to cover, how the services are to be covered, the target populations for the services, eligibility requirements, and other assurances. There is no limit on the number of waivers that can be granted to a state. The federal share of the program ranges from 50% to 80% depending on the state federal Medicaid assistance percentage.

Eligibility

The Task Force on Technology Dependent Children (1987) provides the following discussion:

> Eligibility is limited to Medicaid recipients who, in the absence of HCB services, would require long term care in a hospital, skilled nursing facility, or ICF/MR. States may restrict eligibility for waiver participation to recipients residing in certain geographic areas in the state; to individuals being deinstitutionalized; or to particular individuals for whom the Medicaid cost of providing HCB services is less than the cost of providing institutional care. States may expand income eligibility for the target population in two ways: 1) by not deeming a certain portion of the family's income to be available to the individual receiving care at home; or 2) by raising the Medicaid income limit to a level equal to three times the maximum payment made to an individual under the SSI program... [This is referred to as the "300%" rule.] Individuals becoming eligible under this higher income standard are required to contribute to the cost of their care. (Task Force, 1987, p.102)

Substantial portions of this section were prepared by Gary Smith of the National Association of State Mental Retardation Program Directors.

The "300% rule" may be used for persons who, because of excess income, are not eligible for SSI; would be eligible for Medicaid if institutionalized; and will receive the HCB services. A state may employ the 300% rule (or a variation thereof) only to the extent it applies a similar standard to determine eligibility for institutionally-based services, (i.e. income levels for waiver services can be no more generous than for institutional services). The SSI payment for a couple in June 1989 is $553 per month. The 300% rule therefore allows eligibility for a couple with income up to $1,659 per month.

Unlike a TEFRA state Medicaid plan amendment, a waiver (both the 2176 "regular" waiver and the "model" waiver described next) permits a state to limit the waiver of the deeming of a portion of a family's income to a discrete population.

Services provided

States may provide services under the Home and Community Based Waiver that are otherwise not covered by Medicaid, such as homemaker, respite care, personal care services, minor home modifications, non-medical transportation, emergency response systems, family consultation, habilitation and supported employment programs, as well as augmented regular Medicaid services, (i.e., beyond the extent, scope, and duration of the states Medicaid services) such as hourly shift nursing, personal care, medical supplies, durable medical equipment, and other services as approved. Under a waiver, a state may relax limits established for regular state plan services when such services are furnished to a waiver recipient; a state is not required to meet medicaid "statewideness" or "comparability" requirements; and a state may authorize Medicaid services it does not cover under the state plan. Where it can be shown to be cost effective, the waiver may also be used to pay for an individual's private insurance premiums. Recent amendments to the waiver include employment related services and supported employment as allowable HCB services.

Restrictions on Waiver Programs

In adopting Section (1915)(c) of the Social Security Act, Congress mandated that a state must demonstrate that the average annual per capita costs of HCB waiver services would not exceed the average costs of institutional services (e.g., ICF/MR, hospital, or nursing home payments) that would otherwise be furnished to waiver recipients. In its implementing regulations for Section 1915(c), the Health Care Financing Administration (HCFA) promulgated a complex formula, designed to assure that a state's proposed HCB waiver program was cost-effective. The essence of this formula is that, in order to gain HCFA's approval of its HCB waiver application, a state must demonstrate that spending on long-term care services (HCB waiver and institutional services) while a waiver is in effect will not exceed expenditures that would have occurred in the absence of a waiver program.

HCFA provisions permit a state to develop waivers specific to individuals with specific conditions and gauge cost-effectiveness against the costs of institutional services furnished to this subset of clients. Hence, in targeting waiver services to

ventilator dependent children the costs of furnishing hospital-based services to such children may be employed rather than the average costs of all hospital services.

In practice, HCFA requires that a state demonstrate that: (a) not only will long-term care per capita expenditures under a waiver not exceed those projected to occur in the absence of offering waiver services, but also that (b) the number of persons receiving long-term care services in a state will be no greater as a result of offering waiver services. HCFA's waiver request/renewal process includes considerable negotiation concerning projected long-term care caseloads. In the end, the projected caseload constitutes a "cap" on a state's utilization of long-term care services on behalf of the target population. If, with a waiver, a state failed to effect a reduction in long term hospitalization, HCFA would question the effectiveness of the program.

As a consequence, the HCB waiver program is an anomaly among Medicaid-reimbursable services. Whereas for other services, a state may not overtly limit provision of services to a fixed number of recipients, a state must do so in its HCB waiver program. Consequently, an HCB waiver program is not immediately expandable due to increased recipient demand. Federal review criteria also place a large premium on the deactivation of state institutional beds in order to expand waiver services. Finally, the HCFA formula itself creates a substantial financial disincentive to offering lower cost services to waiver recipients. The waiver formula does not permit states to realize the savings of offering lower cost services and then to offer these savings to new persons. Therefore states tend to develop waivers for relatively higher cost services, thereby obtaining more federal dollars, rather than opting to offer the less expensive in-home services. This a key factor behind explaining why in-home services typically do not command a significant share of HCB waiver spending in most states.

State Participation

Presently 39 states operate HCFA-approved HCB waiver programs targeted to serving persons with developmental disabilities. The scope and range of services offered under these programs varies enormously. As a consequence, determining whether services are available under a state's waiver program that could play a role in meeting the needs of children at home requires an examination of the particular state's waiver program provision.

MODEL WAIVERS

Purpose

The so-called "Model Waiver" option was developed by HCFA to create a streamlined process for a state to offer home and community-based services (under Section 1915(c) of the Social Security Act) to a relatively small number of individuals. This program was intended to replace the case-by-case waiver requests that emerged as an outgrowth of the "Katie Beckett" case which allowed states to redeploy Medicaid funds for inpatient services to the support of in-home services. However, the "Model Waiver" program establishes no special opportunities to initiate home services for children with severe disabilities apart from generalized statutory authority governing the home and community-based waiver program. Structurally, there is no substantive difference between the model and the "2176" waiver program. The chief distinguishing characteristic of "Model Waiver" programs has been their size and the types of services/individuals states typically target. The model waiver represents an opportunity for a state to more discretely target waiver services to a participating client subpopulations (e.g., ventilator dependent children living at home), and the model waiver is generally oriented to serving children living at home. Until the passage of OBRA-87 in December, 1987, HCFA restricted the size of Model Waiver programs to no more than 50 individuals. Under OBRA-87, Model Waivers serving up to 200 individuals are now permitted. A state may propose to operate two or more model waiver programs and may operate a model waiver in addition to or in lieu of a regular section 2176 waiver. If a state already has a 2176 waiver, the model waiver application form permits the state to avoid repeating some material in its request.

Eligibility

Model Waiver eligibility criteria parallel those employed for the 2176 home and community-based waiver program. HCFA encourages a state to utilize the Model Waiver mechanism when it is seeking to cover a relatively small number of individuals. In addition, where coverage of children living at home is desired, HCFA also encourages (but does not mandate) that a state consider concurrently applying for a waiver of the "deeming" of parental income as a means of broadening eligibility for Model Waiver services. A state, however, may apply for a waiver of "deeming" when it is seeking HCFA approval of a "regular" HCB waiver program application.

Services Provided

While a state may propose to include an array of medical and non-medical services in a Model Waiver program application, HCFA guidelines urge states to restrict Model Waiver programs to a limited set of services. As with a "regular"

This section was largely prepared by Gary Smith of the National Association of State Mental Retardation Program Directors.

waiver program, a state may propose to cover medical services not otherwise furnished under its state Medicaid plan and to augment the extent, scope and services available under the state plan.

Other Notes

In most instances, states have employed the Model Waiver program to extend Medicaid coverage to relatively discrete, low-incidence target populations. Since utilization of home and community-based services is capped, some states have found the Model Waiver program to be a preferable alternative in covering home care services for children with severe disabilities to opting to add TEFRA 134 coverage under the state Medicaid plan. Like "regular" waiver programs, however, the Model Waiver program cannot be viewed as a means of achieving broad-based Medicaid coverage of non-institutional services. A "model" waiver may be appropriate in the case where the services a state wishes to furnish vary markedly from those that would be furnished under its regular waiver or if the institutional costs that would be incurred in the absence of a waiver are differentially higher than settings such as an ICF/MR.

WAIVER PROGRAM FOR "BOARDER BABIES"

The Congressional Research Services reports (1988):

> The Medicare Catastrophic Coverage Act of 1988 (Public Law 100-360) establishes a new waiver program targeted at "boarder babies," children who are infected with the acquired immunodeficiency syndrome virus (AIDS) virus or who are drug dependent at birth and who may remain in hospitals indefinitely because of problems in finding an alternative placement. The new 1915(e) waivers will allow states to provide services to such children, as well as to any children with AIDS, who (i) are under age 5, (ii) are receiving or are expected to receive federally funded adoption or foster care assistance, and (iii) would be likely, in the absence of waivered services, to require the level of care provided by a hospital or nursing facility. Covered services could include nursing care, physicians services, respite care, prescription drugs, medical devices and supplies, transportation, and any other service requested by the state and approved by the Secretary.
>
> As with other home and community-based services waivers, the state is required to provide assurances that the health and safety of waiver participants will be protected, that there will be financial accountability for program funds, and that the projected per capita cost of the program will not exceed the costs that the Medicaid program would have incurred for the same individuals in the absence of a waiver. (p. 343)

MEDICARE

Purpose

The purpose of the Medicare program is to provide hospital insurance protection and medical care insurance for covered services to any person aged 65 or above, to certain persons with disabilities, and to individuals with chronic renal disease. Medicare hospital insurance (Part A) is financed by Social Security payroll contributions and matching contributions from employers. There is no state financial participation, although states may "buy into" Medicare coverage for certain eligible Medicaid recipients. Medicare medical insurance (Part B) is available to eligible persons on a voluntary basis.

Eligibility

The only children under age 18 who are eligible for Medicare are those with end-stage renal disease, (except in the unlikely event that a child is a beneficiary of SSDI through their his or her own work history). The following category of adults are eligible for Medicare:

- Disabled adults under age 65 who have been entitled to Social Security Disability benefits for at least 24 months. This applies to both the disabled worker who is the primary beneficiary of SSDI as well as the disabled adult offspring of the primary worker that had been receiving SSDI benefits as a family member or a disabled worker.

- All persons age 65 or over who are entitled to monthly benefits under the Social Security Old Age benefits or railroad retirement programs.

- All adults receiving SSDI benefits, and their children and spouses, with end-stage renal disease who require renal dialysis or kidney transplant.

All persons aged 65 or older (except aliens) and all persons with disabilities entitled to Medicare Hospital Insurance are also eligible to enroll in the Medicare Medical Insurance (Part B) program on a voluntary basis by paying a monthly premium (usually deducted from the monthly social security check). Federal

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Assistance with this section was provided by Delores Cashman of the Health Care Financing Administration, by publications of the Health Care Financing Administration, and by Allan Bergman of United Cerebral Palsy Associations.

monies supplement the paid monthly premiums to cover Medicare Medical insurance benefit administrative costs. State welfare agencies may "buy in" to Medicare on behalf of public assistance recipients and pay the premium. Under "buy in" programs, Medicare pays for benefits which Medicaid would otherwise be required to cover.

Services covered

Hospital insurance (HI) benefits are paid to facilities to cover the reasonable costs of medically necessary services furnished to individuals entitled under this program. Medicare will pay for services that are "reasonable and necessary" for the diagnoses and treatment of an illness or injury. It will not pay for "custodial" care such as assistance in daily living activities. In general, hospital insurance covers hospital care, skilled nursing, home health care and hospice care. There are limits on the amount of these services that are covered. The voluntary medical insurance will pay for 80% of Medicare's approved charge (after a small deductible) for: physicians and surgeons services, home health service, hospital service and other medical and health services.

Medicare Catastrophic Coverage Act of 1988

This act is the first major legislative expansion of Medicare since its enactment in 1965. Hospital insurance was broadly expanded from providing 60 days of free hospitalization per "spell of illness" to unlimited free hospital care after payment of an initial annual deductible. In addition, out-of-pocket expenses for doctor bills (under Part B) are capped at $1,370 a year. Beginning in 1991, Medicare will pay 50 percent of the cost of outpatient prescription drugs in excess of $600 per year. Home health care coverage is also expanded. Beginning in 1990, "intermittent" skilled nursing care can be provided for up to 39 continuous days of home care, seven days a week, at one or more visits per day. Under the new law, Medicare will also pay 80 percent of up to 80 hours of in-home care a year for persons who are "chronically dependent." Services include homemaker, home health aides, personal care and nursing care to provide respite to families who are providing long term care support to the Medicare beneficiary. The beneficiary must need assistance with at least two basic activities of daily living. The new Medicare benefits will be financed by new premium increases. The premium increases are tied to an individuals adjusted gross income, reflecting a change toward an income tested program (Bergman 1988a).

CIVILIAN HEALTH AND MEDICAL PROGRAM OF THE UNIFORMED SERVICES (CHAMPUS)

Purpose

The U.S. Department of Defense provides to health care for family members of military personnel through two interdependent systems: 1) military treatment facilities (i.e. hospitals and clinics); and 2) the CHAMPUS program which supplements and shares the costs of care not available in military treatment facilities.

Eligibility

Those eligible for CHAMPUS are family members of military personnel.

Services offered

CHAMPUS offers regular home health benefits - including durable medical equipment, oxygen, physical therapy, skilled nursing care, medications and medical supplies and physician visits. CHAMPUS also has a special program for active duty military personnel which provides financial assistance when a member's child with moderate or severe mental retardation or physical handicaps is excluded from appropriate public programs or institutions. The Program for the Handicapped (PFTH) authorizes benefits including diagnostic services, inpatient, outpatient and home treatment, rehabilitation, training, special education, institutional care, durable medical equipment and supplies, transportation, and skilled hourly nursing care. The PFTH is limited to a maximum of $1,000 per month. CHAMPUS does not provide for "custodial care" defined as care for persons who require assistance to support the essentials of daily living and not "active treatment" to reduce dependency so that the patient can function outside of a protected environment. If a child is determined to be "custodial" the child is only eligible for limited home care benefits.

There is presently a Home Health Care (HHC) demonstration project for family members of active duty personnel. Persons who would otherwise be receiving hospital care can receive extensive home health services -- including skilled hourly nursing -- and related community support services which are medically necessary, appropriate and cost-effective. The program excludes persons requiring "custodial care" and applicants must meet "level-of-care" requirements.

Information for this section was derived from Task Force (1987).

MATERNAL AND CHILD HEALTH BLOCK GRANTS

Background

The Omnibus Reconciliation Act of 1981 created a single Maternal and Child Health (MCH) block grant which replaced many categorical grants originating under Title V of the Social Security Act of 1935. Some of the categorical grants were for: Crippled Children's Services; Maternal and Child Health; and Disabled Children's Services. Under the block grant, federal requirements for specific programs were eliminated and states were granted wide flexibility over the structure, target populations and services. Under the MCH block grant (often still referred to as "Title 5"), every four federal dollars must be matched with three state dollars. Aside from the block grant, the federal appropriation for maternal and child health also funds other specified projects.

Purpose

There are four federal priorities that are outlined for the use of the Block Grant. They are:

- To assure access to quality maternal and child health service, especially for those with low income;
- To reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children, and to reduce the need for in-patient and long-term services;
- To provide rehabilitation services for individuals who are blind or who have disabilities under age 16 receiving SSI; and
- To provide assistance to children who are in need of special health care services by efforts to locate them, by assuring medical and other supportive services and care, and by assuring availability of health care facilities.

Assistance with this section was provided by Harriet Fox of Fox Health Policy Consultants, the U.S. Office of Maternal and Child Health and publications from the Office of Maternal and Child Health.

Of the total congressional appropriation for Maternal and Child Health, roughly 85% goes to states, on the basis of specified formulas, as the Maternal and Child Health Block Grant.

Roughly 15% of the congressional appropriation (known as the federal "set-aside") goes to fund discretionary grants referred to as Special Projects of Regional and National Significance (SPRANS).

The SPRANS include five grant categories: Maternal and Child Health Research (development and application of new knowledge to the health problems of mothers, children and children with special health care needs); Maternal and Child Health Training (leadership training in specialized health professions); Genetic Disease Testing, Counseling and Information Dissemination; Hemophilia Diagnostic and Treatment Centers (serving as a demonstration model for issues relating to regionalization of treatment of low prevalence conditions); Maternal and Child Health Improvement Project (the creative modification of maternal and child health care systems to improve health status). The SPRANS grants are awarded on a competitive basis to a variety of applicant organizations. Nearly 500 SPRANS grants were awarded in 1988.

Congressional appropriations for maternal and child health that exceed a certain ceiling are earmarked for other specific purposes. A designated percentage of the funds that exceed the ceiling, is used for grants to fund projects for the screening of newborns for sickle cell anemia. Another percentage above the ceiling is allotted for the development of child health demonstration projects that provide primary health care services to all children and to promote community-based service networks and case management services for children with special health care needs.

Eligibility

Maternal and Child Health Block grants fund a variety of programs. Eligibility for programs is determined by the state and may focus on particular subsets of children. Federal law prohibits imposing fees on low-income women and children. Where fees are imposed, they must reflect the income, resources, and family size of beneficiaries. Some states have sliding fee schedules (Task Force, p. 107). Many states have expanded service eligibility to include children with a wide range of chronic health conditions (Task Force, p. 106).

Services provided

State applications for Maternal and Child Health Block Grants must include a statement of goals and objectives and of services to be provided. Many states use the block grants to continue to fund the previously existing categorical programs (e.g., Crippled Children's Services and Maternal and Child Health).

The Task Force on Technology Dependent Children provides the following description of services provided by some states under the block grant through their state Children with Special Health Care Needs (CSHN) programs (formerly called Crippled Children's Services).

> Services offered in state Children with Special Health Needs Programs are diverse and extensive. Most states spend program funds on screening and treatment of handicapping conditions. They also fund a variety of ongoing support services, including case management and counseling. State CSHN services are typically provided through state health agencies and physicians on a fee-for-service basis. In most states, CSHN is a strongly clinic-based program, both providing and reimbursing for covered services. CSHN is often coordinated with Medicaid with CSHN providing services and Medicaid reimbursing the clinic for services provided to Medicaid eligible families. Despite its traditional clinic-based emphasis, most CSHN programs fund or provide varying amounts of home care services such as home nursing and respite care as well as case management and training for families. (Task Force, 1987, p.107)

Under the special allotment to states earmarked for primary care services for children and specialty services for children with special health care needs, many states have initiated new programs. Many states have focused on providing case management rather than community-based service networks. Some programs have restricted resources to particular sub-populations of special needs children (Fox, 1988).

SPRANS projects have also added to the range or services available to children with chronic illness or severe disability. Programs in Illinois, Louisiana and Maryland aimed at developing long term care for ventilator-dependent children, including a regionalized system of care and a comprehensive coordinated care model (Task Force, p.108). Family support projects have begun in New York and Oklahoma and other projects have focused on coordinated community-based care. A directory of all SPRANS projects is available through the National Center for Education in Maternal and Child Health in Washington.

TECHNOLOGY ASSISTANCE ACT

Purpose

This recent act establishes a new competitive state grant program to assist states to develop and implement a consumer-responsive statewide technology related assistance program. Some of the state purposes of the grants are to: increase awareness of the needs of individuals with disabilities for assistive technology services; increase the availability and funding for the provision of these assistive technology devices; increase the knowledge of the efficacy of assistive technology devices among individuals with disabilities and related persons; and, increase the capacity of public and private entities to provide technology related assistance.

Eligibility

Recipients of the grant activities are defined as persons who are considered to have a disability by any other state or federal law and who would be enabled by assistive technology to maintain a level of functioning or achieve a greater level of functioning in any major life activity.

Three year grants are made to states who submit applications. The amount of the award is based on the overall appropriation from Congress, the population of the state or territory, and the types of activities proposed by the state in their application. The law states that there should be an equal geographic distribution of states receiving grants. In the first two years of the three year grant, a state may receive between $500,000 and $1,000,000. In the third year a state may receive as much as $1,500,000.

Services

Franklin (1988) reports that "States can use the funds under this act to carry out any of the following activities:

- Model Delivery Systems -- Under the Act, a state may support the development of model systems for the delivery of assistive technology and services that can be replicated.

- State-wide Needs Assessment -- The state may conduct a statewide needs assessment which may be based on already existing data and may provide states with information on the scope and type of services to be provided. Under the needs assessment, states are also to investigate funding sources available for the payment of assistive technology.

- Support Groups -- The state may use funds to encourage the creation or maintenance of community-based organizations or systems that assist individuals with disabilities to use assistive technology or devices.

- Public Awareness Programs -- The state may fund public awareness programs designed to provide information on assistive technology designed to educate a wide audience of individuals on assistive technology.

- Training and Technical Assistance -- Funds for this program may be used to support training activities which relate to the provision of assistive technology services. The training can include individuals with disabilities and their family members as well as individuals who work for public agencies or private entities that have contact with individuals with disabilities.

- Access to Related Information -- The state may develop, operate or expand a system for public access to information systems.

- Interagency Agreements -- The state may enter into cooperative agreements with other state agencies to expand the capacity of the state to assist individuals with disabilities to learn about, acquire, use, maintain, adapt, and upgrade assistive technology and services.

- Other Activities -- The state may use its funds for any other activities necessary for developing, implementing, or evaluating a state-wide service delivery system,". (p. 4)

Title II of the act authorizes a variety of discretionary studies to be performed by the federal government including: a study on financing assistive technology; a national information and program referral network; training and public awareness project; and demonstration and innovation projects.

INCOME SUPPORT

SUPPLEMENTAL SECURITY INCOME (SSI)

Purpose

SSI provides monthly payments to children who are blind or disabled whose family income and resources are below specified levels. SSI is also available to low-income adults with handicaps or who are over age 65. Eligible persons receive a basic standard federal grant ($368 per month at present for single persons and $553 per month for couples) that is 100% federal funded. Persons with some income who do not qualify for the whole grant may receive a partial SSI grant. Some states also offer supplemental payments above the federal grant to eligible individuals (including children). State supplements are 100% state funded. Some state supplement programs contain provisions to make payments on behalf of individuals with disabilities for home care services or to meet the costs of board and care. States may choose to offer some or all of the supplemental grant to children and adults who do not meet income restrictions for the basic federal grant but are under state specified income levels for the supplemental grant.

Eligibility

According to present Social Security Regulations (Social Security Administration 1977), children under age 18 are eligible for SSI when they have a disability or impairment (or the medical equivalent) that is included in the Social Security "List of Impairments" and if the child meets income and assets eligibility criteria.

The disability eligibility criteria are currently being tested in federal court. Under the original Social Security Act a child was considered to be disabled if s/he had a disability that was comparable in severity to one that enabled an adult to qualify. Adult qualifications rest on assessments of whether their disability prevents the individual from engaging in substantial gainful activity. Advocates argue that children should receive a comparable individual assessment of functional limitations to determine eligibility rather than exclusive reliance on a list of impairments. According to a recent third circuit federal court of appeals decision in Philadelphia, the Social Security Administration eligibility procedures are too restrictive. This decision overturns a 1986 ruling by a federal district

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Portions of this section were prepared by Gary Smith of the National Association of State Mental Retardation Program Directors. Information was received from Roy Trudell of the Health Care Financing Administration, Harriet Fox of Fox Health Policy Consultants and publications by the Social Security Administration.

court that upheld SSA's requirements (Mental Health Law Project Update, 1988; Association for Retarded Citizens, 1988).

In determining a child's income, a portion of the family's income is "deemed" available to the child if the child is living with his or her family. Therefore children living with families that have moderate income, and in some cases low income, may be excluded from SSI benefits. For children who are living out of the home (e.g., institutionalized or living in an Intermediate Care Facility) for more than 30 days, family income is not deemed; and the child may therefore become eligible for SSI. This policy, however, may foster out-of-home placement.

Adults are eligible for SSI if, after exclusions, an individual's income does not exceed $354 per month and resources do not exceed $1,900. These eligibility criteria do not vary across state. States do vary, however, in the resource requirements for the state supplemental grant for both adults and children. States also impose other restrictions on SSI supplemental payments for home care or residential "board and care."

Services provided

The maximum federal SSI payment for an eligible adult or child is $368 a month. The maximum payment may be reduced to reflect other recipient income. No limitations are placed on types or kinds of expenditures to which federal SSI payments may be put. Once a child is eligible to receive SSI payments, they are also automatically eligible for Medicaid in all but thirteen states (see page 6) provided a state has entered into a Section 1634 agreement with the Social Security Administration.

State supplemental programs vary enormously in their scope. Supplementation may provide only minimal additional cash assistance to SSI recipients or may include provision to assist elderly persons and/or persons with disabilities to receive "home care" services or meet the costs of "board and care" in residential settings. To determine whether a states supplemental program is pertinent to meeting the needs of children, a careful review of the particular state's program is required.

Individuals living in institutions do not receive SSI grants. However, many children placed in institutions (no longer having parents income "deemed" available to them) become eligible for SSI and therefore eligible for Medicaid and for Medicaid payments to the institution they are residing in. Such children also receive a small cash allowance for "personal and incidental expenses" from the Social Security Administration. Thirty dollars a month is placed in a trust fund for children and adults living in institutions for their personal use.

Incentives for Employment

P.L. 99-643, the Employment Opportunities for Disabled Americans Act, passed in July 1987 makes it easier for SSI recipients with disabilities to work and protect benefits while allowing recipients to test their work capabilities. In particular it allows continued Medicaid protection for SSI recipients whose earnings are too high for SSI cash payments as long as they remain medically impaired, need Medicaid in order to work, and cannot afford to replace Medicaid benefits. These provisions are reflected in Section 1619(a) and 1619(b) of the Social Security Act.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

Purpose

The purpose of SSDI is to replace part of the lost wages resulting from a physical or mental impairment severe enough to prevent a person from working. SSDI is provided to workers who have paid into the Social Security system and are unable to continue working because of disability. Unlike SSI, SSDI is based on employment history and it is not "means tested" (i.e., not based on income). Over the years SSDI has been expanded to include cash benefits to certain family members of a worker with disabilities who is "insured" and is receiving SSDI benefits. All minor age children (including children with disabilities) of an insured worker can receive a portion of the insured parent's benefit amount. Presently, children of an insured worker who are over age 18, are unmarried and who became disabled prior to age 22 can also receive SSDI benefits.

Eligibility

SSDI is available to minor children (whether disabled or not) if their parent is a worker with disabilities receiving SSDI benefits. SSDI benefits are also available to minor age children in their own right if they have earned wages for about 1.5 years, have paid into the social security system, and have subsequently become too disabled to work. (This is most often relevant to working teenagers over age 16). Unmarried adults (over age 18) who have acquired a disability prior to age 22 can also receive disability benefits if they have a parent receiving SSDI.

An adult worker under age 65 is eligible for SSDI if s/he has earned wages for a sufficient period of time and has become too disabled to work. SSDI benefits are extended to other family members of a beneficiary, i.e. a spouse aged 62 or over under certain conditions, and a spouse of any age who is caring for a minor age child or child with disabilities over age 18, when the child is receiving SSDI benefits.

Assistance with this section was provided by Delores Cashman of the Health Care Financing Administration and by publications of the Health Care Financing Administration.

Services Covered

Monthly cash benefits are paid to the eligible worker and to the eligible family member throughout the period of the worker's disability after a 5-month waiting period. There are no restrictions on the use of benefits received by beneficiaries.

Cash benefits to eligible persons are based on work history. Average monthly benefit rates are $508 for an individual and $919 for an individual with a family. Family members who receive SSDI benefits, including adult offspring with a disability, receive a portion of the benefit rate available to the insured worker. Once an individual is receiving SSDI for 24 months the beneficiary becomes eligible for Medicare. The eligibility of Medicare does not apply to children under age 18 whether or not the child has disabilities. Once a child turns 18, however, s/he can then be eligible if s/he has had a disabling condition with an onset before age 22.

Note: An SSDI provision which potentially will benefit people with severe disabilities is the requirement that workers in non-profit organizations be covered. This means that people with severe or profound retardation working in sheltered workshops and earning as little as $400 per quarter could qualify for disability insurance and be entitled to cash benefits, Medicare coverage and retirement income.

SOCIAL SERVICES

SOCIAL SERVICES BLOCK GRANT

Purpose

The Social Services Block Grant (SSBG) enables each state to furnish a variety of social services directed toward one of the five goals specified in the law (see below). SSBG (often referred to as "Title 20" based on its authorizing statute) is a 100% federally funded program but federal allocations to individual states are limited by a federal authorization cap ($2.7 billion in 1987). Each state receives a federal grant-in-aid to support social services from a population-based grant formula. States must submit approved plans of service to receive funds.

Eligibility

Each state establishes its own eligibility requirements.

Services covered

Federal funds may be used for the proper and efficient operation of social service programs to enable eligible individuals to:

- Prevent, reduce, or eliminate dependency;
- Achieve or maintain self-sufficiency;
- Prevent neglect, abuse, or exploitation of children and adults;
- Prevent or reduce inappropriate institutional care;
- Secure admission or referral for institutional care when other forms of care are not appropriate.

Federal funds cannot be used for the following without a waiver from the Secretary:

- For the purchase or improvement of land, construction, or permanent improvement of land; or the purchase, construction, or permanent improvement of any building or other facility;

Assistance with this section was provided by Gary Smith of NASMRPD.

- For the provision of cash payments for costs of subsistence or the provision of room and board;

- For the payment of wages of any individual as a social service; or

- For the provision of medical care unless it is an integral but subordinate part of a social service for which grants may be used.

In no instance, may funds be used for:

- Social services provided in and by employees of any hospital, skilled nursing facility, intermediate care facility, or prison, to any individual living in such an institution;

- For the provision of any educational service which the state makes generally available to its residents without cost and without regard to their income;

- For any child day care services unless such services meet applicable standards of state and local law; or

- For the provision of cash payments as a service.

States have used SSBG funds for a wide variety of services including: child welfare, transportation, day care, case management, and work activity programs. While federal SSBG funds represent one of the most flexible sources of federal financial aid, the fixed funding level of this program yields few if any opportunities to initiate new services.

CHILD WELFARE SERVICES

Purpose

Title IV B of the Social Security Act provides federal funds to develop alternatives to foster care placement or to reunite separated children and families, and to encourage protections for children to ensure they enter out of home care only when necessary, are placed appropriately, provided quality care, reviewed periodically, and provided permanent families in a timely fashion. The Child Welfare Services State Grant Program is 100% federally funded but limited by a fixed federal authorization level. States with acceptable plans receive their share of the total federal appropriation for that year.

Eligibility

Child welfare services must be available on the basis of need for foster care services and often revolve around cases of abuse or neglect. Eligibility for services is not means tested, nor can serviced be denied on the basis of length of residence in the State.

Services covered

Services may include:

- 24-hour emergency caretaker, and homemaker services;
- day care;
- crisis counseling;
- individual and family counseling;
- emergency shelters;
- procedures and arrangements for access to emergency financial assistance;
- arrangements for the provision of temporary child care;
- home family services;
- self-help groups;

- services to unmarried parents;
- mental health, drug or alcohol counseling;
- vocational counseling or rehabilitation; and
- post adoption services.

FOSTER CARE AND ADOPTION ASSISTANCE

Purpose

This program (sometimes referred to as "Title 4E" based on its authorizing legislation) amends the original child welfare provisions of Title IVB of the Social Security Act. The goal of the program is to provide financial assistance and technical consultation to states to make changes in their child welfare systems. Desired changes are:

- To reduce the number of children entering foster care - the law emphasizes the use of preplacement preventive services to help solve or alleviate family problems that would otherwise result in the child's removal from the home;
- To prevent unnecessary separation of the child from the parents;
- To improve quality of care and services to children and their families;
- To bring about permanency through reunification with parents or through adoption or other permanency planning.

The Act also provides federal assistance to states to facilitate the adoption of children with special needs (e.g., mental, physical, or emotional handicaps) by subsidizing monthly payments to families who adopt special needs children. Federal reimbursement is given to states for foster care maintenance payments of AFDC or SSI eligible children who are in foster care, who cannot be returned home, and who have special needs which make it difficult to place them with adoptive families without assistance. Foster Care and Adoption Assistance is 100% federally funded. Each state gets an allotment based on a formula of the number of AFDC children in each state.

Eligibility

Families do not have to meet income limits to receive Adoption Assistance payments, but the children must be eligible for AFDC and/or meet the disability requirements of Supplemental Security Income programs for the family to receive federal reimbursement for foster care payments or adoption assistance respectively.

Services covered

Monthly payments are made to families who adopt or provide foster care to special needs children. Children receiving federally reimbursed adoption assistance payments are automatically eligible for Medicaid after adoption regardless of the adoptive familys' eligibility for Medicaid.

Additional funding to states made available under P.L. 96-272 requires a foster care inventory, annual goals for children who remain in foster care more than 24 months, services to facilitate family reunification, case plan and case review procedures.

ABANDONED INFANTS ASSISTANCE ACT

Purpose

Title I of this recent act provides grants to states and private non-public entities for demonstration of projects aimed at services to infants and young children who were abandoned in hospitals. These "border babies" usually include infants with AIDS and infants exposed to drugs taken by their mother during pregnancy.

Eligibility

The law defines "abandoned infants and young children" as those youngsters who are medically cleared for discharge from acute care hospital settings, but who remain hospitalized because of a lack of appropriate out-of-hospital placement alternatives. The specific population served will depend on the criteria of the particular state demonstration.

Services

The demonstration grants are made available to states for the purpose of developing, implementing, and operating projects to demonstrate methods:

- To prevent the abandonment of infants and young children
- To identify and address the needs of abandoned infants and young children, particularly those with AIDS
- To assist abandoned infants and young children to live in their natural homes or in foster care homes
- To recruit, train, and retain foster families for these children
- To carry out respite care programs for natural and foster families, and
- To recruit and train health and social services personnel to work with natural and foster care families and with residential programs.

DEVELOPMENTAL DISABILITIES ACT

Purpose

This act, originally passed in 1984 and reauthorized with modifications in 1987, aims to enable persons with developmental disabilities to achieve their maximum potential through increased independence, productivity, and integration into the community through formula grants to states. The act enumerates several priority areas on which states are required to expend at least 65% of its annual allotment. A new federal priority area is family support. Family support services must be designed to:

- strengthen the role of the family as the primary caregiver;
- prevent out-of-home placement;
- reunite families with family members who have been placed out of the home; and
- maintain family unit.

Other priority areas include: community living, employment, child development activities, and case management.

Eligibility

Federal grants are made to states to fund a variety of programs. All persons who are the recipients of the federally funded activities must have developmental disabilities. The federal definition of developmental disabilities is "functional." It defines developmental disabilities as the presence of functional limitations in major life areas (e.g., learning, self-care, mobility). This is in contrast to the previous "categorical" definition that defined developmental disabilities by the diagnoses of specific conditions (e.g., mental retardation, cerebral palsy).

Information for this section was derived from "President signs DD extension bill" (1987) and "Developmental Disabilities Act becomes P.L. 100-146" (1987). Full citations are in the reference section.

Services

The federal allotment to each state funds four major components. The Protection and Advocacy agency in each state promotes the rights of persons with developmental disabilities through legal, administrative and other appropriate remedies. They also have the authority to investigate incidents of abuse and neglect. The University Affiliated Programs (UAP) provide inter-disciplinary training to prepare professionals to work in the field of developmental disabilities. The UAPs also administer training grants that address needs in areas of emerging national significance (e.g., aging, early intervention). Special project grants support studies and activities of national significance.

The basic state grant program assists states in planning and conducting activities for the benefit of individuals with developmental disabilities. This is done through the Developmental Disabilities Planning Council in each state. The councils administer their allotment and make grants to programs that support research and planning activities and that provide direct care service. Sixty-five percent of the allotment must be expended on the designated federal priority areas. Thirty-five percent of the allotment is used for planning, coordinating, and administering the priority area activities.

CRISIS NURSERIES AND RESPITE CARE

Purpose

This program (originally passed in 1986) received funding in 1988. Funding is for demonstration or service programs that provide temporary respite care services for children with handicaps or chronic illness to alleviate social, emotional and financial stress among families responsible for their care. Grants are also available for nurseries for children in crisis because of abuse or neglect or who are at risk of abuse or neglect.

Eligibility

Federal grants are made to states, who in turn fund public or private agencies and organizations that provide these services. Grants are made separately for either respite care and/or crises nurseries. States must give preference to agencies experienced in working with children with disabilities and their families. Children who have a handicap (as defined by the Education of the Handicapped Act P.L. 94-142.) or chronic or terminal illness. To receive crisis nurseries service children must have been or are at risk to be abused, neglected, or from a family receiving protective services.

Services

Awarded agencies provide in-home or out-of-home respite care services (short-term, non-medical child care) to children with handicaps or crisis nurseries to children who are abused or neglected. Agencies may be hospital supervised or community based. Services be provided on a sliding fee scale with hourly and daily rates. Services may include: 24 hour services; access to primary medical services; referral to counseling/therapy services; staff training; and, public awareness programs.

Congress has appropriated $5 million for this program in FY 1989 that is to be spent equally on respite services and crisis nurseries. Recently the Department of Health and Human Services awarded 27 states a total of 32 grants (Extension of Temporary Child Care for Handicapped Children P.L. 100-403. *Word from Washington*, October/November 1988). Successful applicants must contribute $1.00, secured from non-federal sources for $3.00 received in federal funding.

STATE SPONSORED FAMILY SUPPORT AND CASH SUBSIDY PROGRAMS - MICHIGAN PROFILE

Introduction

While federal funding can provide significant financing opportunities for family support services, programs that are the most flexible and attuned to the needs of families are often funded by state dollars. Many states have initiated family support programs designed to serve the needs of families that are taking care of a member with disabilities. The supports provided by these programs vary enormously. Typical supports include respite, family education or counseling, and housing modifications. Programs also vary in their eligibility requirements, numbers of families served, limits on supports offered and so on. The purpose of most programs is to improve family caretaking ability by reducing stress, or conversely by increasing coping abilities, and thereby reducing the need for out-of-home placement. A national survey of family support programs is available in Agosta, et al. (1985).

A particularly unique approach to family support programs is family subsidies. These programs provide direct cash, vouchers or reimbursements for purchases made by the family. These programs are usually more flexible than family support programs providing families greater discretion over the kinds of supports they can purchase and over the provider of the service. A description of eight state cash assistance programs is also available in Agosta et al. (1985).

The wide variation in existing family support and cash subsidy programs precludes a useful synopsis. Instead, a profile is presented here of the Michigan family support and cash subsidy programs. The Michigan program was selected for profile because at this time it represents the most comprehensive array of family supports in this country. In this regard it provides a useful model from which other states can draw.

Michigan Family Support Program

Purpose

The major purposes of the Michigan family cash subsidy and the family support program generally are to: prevent or delay the out-of home placements of severely disabled children, improve the quality of life for families; make it possible to bring children home from institutions and other residential facilities; to provide funding for the special needs of disabled children; and to recognize the contributions made by natural families to the care of their disabled member.

Eligibility

The cash subsidy is available to families: 1) whose taxable income is under $60,000, 2) who has a child living at home, under 18 years of age and 3) who has been assessed by the local educational authority to require special education because of: severe mental impairment, severe multiple impairment, or autistic impairment (these are Michigan specific special education categories).

The general family support service is available to families with children who have a developmental disability. There are no income limits although some services are provided on a sliding fee scale.

Services

The cash subsidy program gives each family the equivalent monthly SSI stipend for adults for each eligible child (approximately $255 in 1988). The subsidy is received as a monthly check. No requirements are placed on parents to provide receipts or other documentation on the purchases made with the subsidy. Parents are not required to submit indications of how they intend to use the money either. No restrictions are made on the use of the cash.

Parents were requested to volunteer in an evaluation of the subsidy program. Results from the first years of the program suggest that parents experienced significant reductions in stress and a significant reduction in the proportion of parents who anticipated placing their child out-of-home at some point as a result of the subsidy. Also, types of purchases made follow family resources. While both lower income and higher income families reported that the most common expenditure of the subsidy was on clothing, those with low income tended to the spend money on food and household expenses, whereas as higher income families spent the subsidy on diapers and recreation.

In addition to the subsidy there are a variety of family support options administered through county mental health boards. Support services include: case management, respite/sitter services, parent/family training and counseling, and therapeutic services.

Policy Context

The programmatic innovation in Michigan has occurred within a policy context which places a premium on providing in home support for families of children with disabilities. In 1984 the Governor announced that no child with a developmental disability will be institutionalized in that state. Further since 1986 the Department of Mental Health has adopted a policy of "permanency planning" for all children served by the system.

The policy of permanency planning is defined as follows:[1]

> **A planning process undertaken by public and private agencies on behalf of developmentally disabled children and their families with the explicit goal of securing a permanent living arrangement that enhances a child's growth and development. Permanency planning for children is directed to securing:**

1) a consistent, nurturing environment;
2) an enduring, positive adult relationship; and
3) a specific person who will be an advocate for the child into adulthood.

Underlying assumptions:

1) It is generally in the best interest of children to remain at home with their family. Therefore, public agencies should first attempt to plan, provide, and coordinate services in such a manner that the integrity of the family unit may be *maintained.*

2) If a child cannot be maintained in the home, it is assumed that a public agency should then give priority attention to the provision and coordination of those services that will facilitate *reunification* of the child with his/her natural home.

3) If reunification of the child with his/her family is not possible, and there is not active parental involvement with the child, the feasibility of adoption planning should be rigorously pursued.

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1 Taken from: Michigan Department of Health. (1986). *Permanency planning for children with developmental disabilities in the mental health system*. Lansing, MI: Author, p. 5-6.

4) For some children, already in care, strengthening the ties with the birth family by increasing the quality of involvement while the child remains in foster care may be the most appropriate permanency planning option. For certain other children, the permanency planning path may include such alternatives as long-term foster care, supplemented by securing an advocate or a guardian.

5) Institutionalization is not considered to be an appropriate permanency planning option.

CHILD AND ADOLESCENT SERVICE SYSTEM PROGRAM (CASSP)

Purpose

This program, run by the National Institute of Mental Health (NIMH), has the over-arching goal to:

> increase the quality and availability of services for seriously emotionally disturbed (SED) children and adolescents and their families, with a special emphasis on the prevention of homelessness and the amelioration of the effects of homelessness. . . . More specifically, CASSP assists States and communities to:

1. Develop leadership capacity and foster interagency coordination at State and local levels and plan for the needs of homeless children and adolescents who are severely emotionally disturbed and for those severely emotionally disturbed children and adolescents at risk of becoming homeless,

2. Carry out research demonstrations which systematically evaluate components of the strategy being used and assess the impact of system changes on the availability, accessibility and appropriateness of care. (National Institute of Mental Health, 1989)

Eligibility

With certain exceptions, services are limited to children under age 18 who have impaired functional ability in the school, family or community. Individual states determine the level of disability required to receive service but consumers of the service should require multi-agency intervention. Consumers also must have a mental or emotional disorder diagnosable under DSM-III-R. The disability must have been present for at least one year or is expected to last more than one year.

Applicants for grants under the CASSP program are limited to designated state-wide agencies of state departments in which responsibility for child mental health services reside.

Material drawn from National Institute of Mental Health (1989). *Mental health services demonstration grants. Child and adolescent service system program. Request for applications.* Rockville, MD: National Institute of Mental Health.

Provisions

There are four types of grant available from the CASSP program:

- *State-level system development grant.* The purpose of this grant is to identify and establish a focal point in the state mental health agency for coordinating CASSP-related activities. The identified unit is responsible for developing a multi-agency mental health system for this population. Grants are also to be used to identify the technical assistance needs of agencies in providing services to SED children and to develop the capacity to provide such assistance. Any states that has not previously been awarded this grant is eligible to apply.

- *Community-level system development grants.* These grants are open to states that have already received a state development grant or who have otherwise established coordinating activities for children with SED. Community level grants are to be used to develop strategies to increase "availability of the full range of appropriate services across multiple agencies for each child in the target population at the community level. In moving toward that goal, a state must define strategies to assure development of local child and adolescent service delivery systems," (NIMH, 1989).

- *State-level capacity building grants.* These grants are designed for states that are unable to identify a focus for system building for SED children. "The primary emphasis of this type of grant is the identification of those groups/individuals who have the capacity to conceptualize and promote system change and/or development of children's mental health service delivery and the strategy to remove barriers to the initiation of system change process at the state level" (NIMH p.5). Activities for this grant must include specified roles for child mental health advocacy organizations, parent support/education groups and related voluntary organizations.

- *Post-CASSP Development Evaluation Grants.* After states have participated in the prior grant projects, they may apply for this grant which evaluates the outcomes of post-CASSP system building. The grant is also used to identify potential barriers to continued system implementation and to develop a plan for overcoming them through the use of CASSP technical assistance resources.

All grants must include evaluations of the outcome of the grant. Costs of delivery of direct client services are not allowed under the provision of these grants.

EDUCATIONAL SERVICES

EDUCATION OF ALL HANDICAPPED CHILDREN ACT (EHA)

Purpose

The Education of All Handicapped Children Act, Public Law 94-142, insures that all children with handicaps between the ages 5-21 have available to them a free and appropriate public education (FAPE) which includes special education and related services to meet their unique needs in the least restrictive environment. Four general purposes are described for the Act.

> "These are (1) to assure that all handicapped children have available to them a free appropriate public education, (2) to assure that the rights of handicapped children and their parents or guardians are protected, (3) to assist States and localities to provide for the education of all handicapped children, and (4) to assess and assure the effectiveness of efforts to education handicapped children," (U.S. Department of Education, 1984).

This law provides for federal assistance to states in order to meet the excess costs engendered by special education on a per child basis. Although the law provides for federal assistance to meet up to 40% of the excess costs of special education, in practice federal assistance to states has been significantly less. Nonetheless the law is best understood to be an entitlement, i.e., a requirement that all children with handicaps receive special education, irrespective of federal assistance (Allan Bergman, UCPA, personal communication).

Eligibility

Federal funds are provided to the state on a match basis to provide for public education and related services for children identified by the state as having a handicap. All children who are so identified are entitled to receive special education services. Children must be determined by a local inter-disciplinary team to require specially designed instruction because of unique needs resulting from one or more of the following impairments: visual impairment, hearing impairment, deaf and blind impairment, mental retardation, multihandicaps, orthopedic impairment, serious emotional disturbance, specific learning disability, speech impairment, or other health impairment. Related services are provided only if the service is necessary for the child to benefit from special education. "Therefore, if a child does not need special education there can be no related services and the child (because not handicapped) is not covered under the Act." (Code of Federal Regulations, Ch. III 7-1-85 Edition). This means that, whereas a child may benefit from a particular service (e.g. physical therapy) but is not considered to require special education, the child will not be eligible to receive that related service.

Services provided

Federal assistance is provided to states on a ratio of 75% to local education agencies for the support of direct educational services to children with handicaps. The remaining 25% is provided to State Education Agencies for administrative and other special expenses of the special education program. States are required to undertake "child find" activities in order to identify all children that require special education. Each child receiving special education must receive an individualized education plan. The plan specifies educational setting and objectives and the need for any educationally related services. Children are to be served in the "least restrictive environment." Numerous rights, protections, and procedures are built into the law so that families can appeal and obtain fair hearings in any decision made by local and state education agencies about their child's educational status or program.

Educationally related services are defined as including: transportation, speech pathology and audiology services, early identification of a disability, medical services, recreation, social work in schools, occupational and physical therapy, psychological services, and medical services for diagnostic and evaluation. Recent legislation clarifies federal Medicaid responsibility to reimburse states for medically "related services" that may be listed in an individual's special education plan and which are covered in the state's Medicaid plan. This is discussed below.

Medicaid and "Related Services"

Attempts have been made by local education agencies to obtain federal Medicaid funding from the Health Care Financing Administration (HCFA) for "related services" listed in the individualized special education plan of a Medicaid eligible child. However, HCFA administrative policies attempted to define any service furnished under an IEP as "educational" in nature and, hence, ineligible for Medicaid payment. The Medicare Catastrophic Coverage Act of 1988 contains a technical amendment clarifying Medicaid reimbursement for covered educationally related services. The amendment serves to clarify that, while state education agencies are responsible for assuring the provision of a free and appropriate public education to all children with handicapping conditions, the state education agency does not have to *finance all services* in a child's IEP. State Medicaid agencies are responsible for reimbursing schools for educationally related services to Medicaid eligible children, to the extent that the services are covered under the state Medicaid plan and that the service be deemed medically necessary. Medicaid agencies make individual case determinations of medical necessity in accordance with their own criteria (Bergman 1988a).

The amendment states that just because a service is listed on a child's educational plan it cannot be disallowed by HCFA.

"While the state education agencies are financially responsible for educational services, in the case of a Medicaid eligible disabled child, State Medicaid Agencies remain responsible for the 'related services' identified in the

child's IEP if they are covered under the State's Medicaid plan ..." (Congressional conference report, quoted in Bergman, 1988a).

EARLY INTERVENTION PROGRAM FOR INFANTS AND TODDLERS

Purpose

Title I of Public Law 99-457 amends the Education of the Handicapped Act (EHA) by establishing a new Federal discretionary program to assist states to develop and implement a comprehensive, coordinated, interdisciplinary program of early intervention services for infants and toddlers with handicaps and their families. This is the first piece of federal legislation that recognizes the role of families as the primary caregivers for their children with handicapping conditions. The program is 100% federally funded.

Eligibility

The legislation defines the eligible population as all children from birth through two years of age who are developmentally delayed (criteria to be determined by each state), or who have conditions that typically result in developmental delay, or at state's discretion who are at risk of substantial developmental delay.

Services

In the first three years of the program, states may use their grants to plan, develop and implement a statewide system for early intervention or to provide direct services. In the fourth year, the state must have a statewide system in place and must provide multidisciplinary assessments, individualized family service plans and case management services. By the fifth year and for succeeding years, the state must assure that the state-wide system is in place as an entitlement and must provide a description of the early intervention services provided to all eligible infants and toddlers.

Early intervention services are defined in the act as developmental services which: 1) are provided under public supervision; 2) at no cost to the family; 3) are provided by qualified personnel; 4) are provided in conformity with the family service plan; and, 5) include: family training, counseling, and home visits; special instruction; speech pathology; occupational and physical therapy; psychological services, case management, and other health related services.

Information for this section was derived from "President Signs Education of the Handicapped Amendments" (Oct., 1986). *Capital Capsule*, 16(10), p.2, Alexandria, VA: National Association of State Mental Retardation Program Directors; and "Section-by-Section Summary of P.L. 99-457"; *Liaison Bulletin*, 12(12), p. 1, National Association of State Directors of Special Education.

The federal grant is meant to assist states to plan and develop the statewide system and to fund direct services and expand and improve services that are not otherwise provided or accessible from other public or private sources. The act includes a "payor of last resort section" which stipulates that grant funds cannot be used to substitute payments for services that would have been paid for from another public or private source.

The state early intervention system must include the following minimum components:

- *an individualized family service plan for each infant and toddler with a handicap in the state, including the provision of case management services in accordance with such plan;*
- *the family service plan must contain information on the infant/toddler's present level of functioning, family strengths and needs, services to be provided and anticipated outcome, and the name of the case manager;*
- a comprehensive, multidisciplinary evaluation of the service needs of each infant and toddler and their families;
- timetables for ensuring that appropriate early intervention services will be available to infants and toddlers with disabilities before the fifth year of the state's participation;
- a comprehensive "child/find" system to locate infants/toddlers with disabilities in need of services;
- a central directory of early intervention services, resources and expertise;
- a lead agency and interagency coordinating council designated by the Governor to administer the program.

Part H funds are allotted to each state based on the proportionate number of infants and toddlers (both disabled and non-disabled) living in the state (not on the number of children served). States are also directed not to reduce medical or other benefits available to infants/toddlers with disabilities under Maternal and Child Health Block Grants or Medicaid because of the grant funds.

FEDERAL PRESCHOOL PROGRAM

Purpose

Under Title II of this recent legislation, all the rights and protections of P.L. 94-142 (Part B) are extended to children with handicaps ages 3 through 5 years by school year 1990-91. To support this objective, the law revises the Preschool Incentive Grant Program (Sec 619) to authorize a dramatic increase in the federal fiscal contribution. By school year 1990-91, all states applying for PL 94-142 funds must assure that they are providing a free appropriate public education to all children with handicaps ages 3 through 5. Failure to comply will mean the loss of EHA funding targeted to the 3-5 age group. Prior to 1991 a state would have to have an approved early childhood education plan and serve some, but not necessarily all children with handicaps between ages 3 through 5. Funds to states are determined by Congressional authorization levels and are allocated by each child served. The maximum basic per capita allowance would increase from$300 to $1,000 per year over a four-year period, provided that congressional appropriations are sufficient to fund these levels.

Eligibility

Those eligible are children with handicaps ages 3 through 5. States are not required to report children served 3 through 5 by disability category. Thus states are not required to categorically label these children according to the data requirements of EHA Sec. 618.

Services offered

During school year 1988-89, a state must distribute at least 75% of federal funds to local education agencies to support educational service to children with disabilities ages 3 through 5. The remaining can be used by state education agencies for planning, administrative and other expenses. The committee report accompanying the legislation affirms variations in length of school day and range and variety of pre-school programs, examples being part-day home and full-day center-based programs. The legislation specifically authorizes parent training as a mandated pre-school service.

HEAD START

Purpose

Project Head Start, presently administered by the Administration for Children, Youth, and Families, provides comprehensive developmental services to low-income pre-school children. The program seeks to strengthen the ability of disadvantaged children to cope with school, enhance parent-child interaction, and bring about greater social competence in children from low-income families.

To accomplish these goals, Head Start objectives and performance standards provide for:

- an improvement of the child's health and physical abilities;
- the encouragement of self-confidence, spontaneity, curiosity, and self-discipline in the child;
- an enhancement of the child's conceptual and communication skills;
- an increase in the ability of the child and family to relate to one another and to others; and
- the enhancement of the child and his/her family sense of dignity and self-worth.

The yearly congressional appropriation (this year over $1 billion) is distributed to states and then to individual Head Start programs. The amount of the appropriation to states is based on the number of Head Start children that the state presently serves. There has been significant expansion in the number of Head Start programs over the past decade.

This discussion is based on publications of the Administration on Children, Youth and Families.

Eligibility

Generally, Head Start is limited to children between three years of age and the age of compulsory school attendance. Since a 1972 Congressional mandate, no less than 10% of the total number of enrollment opportunities in each state must be made available to children with handicaps. In 1986-87 children with handicaps accounted for 12.7% of all children enrolled in full-year Head Start programs. (The definition of children with handicaps is the same one used for special education). Families must also demonstrate that their income is under the designated federal poverty line in order for their child to be eligible.

Services

Many Head Start programs follow the standard model of a five day week with full day sessions. However, alternative program types may be chosen such as part-time programs, a home-based model (where the parent is focused on as the primary factor in the child's development and the home as the central facility), or another locally designed option which is suited to meet the needs of children and families in that particular community.

All Head Start programs must have the following components:

- educational and learning experience (including the provision of bi-lingual staff where necessary);
- a comprehensive health care program including: early identification of health problems through medical and dental screenings, follow-up treatment of medical or dental problems, parent education on health care and nutrition, one hot snack per day, and mental health services (i.e., mental health training and consultation to parents and staff);
- parent involvement through parent education, volunteer or paid positions in the Head Start program (parents receive preference for employment in non-professional Head Start staff jobs), and participation in Policy Councils and Committees concerned with administrative and managerial decisions;
- social services (e.g., community outreach, information and referrals, family needs assessments, recruitment and enrollment of children, and emergency assistance and/or crisis intervention).

Children with handicaps receive the full range of Head Start developmental services. In addition, Head Start staff members coordinate with community agencies to provide services to meet the special needs of these children.

TRANSPORTATION

Assistance with this section was provided by Patricia Brady, United Cerebral Palsy Associations Inc., Governmental Activities Office, Washington DC. Additional questions may be addressed to her. Material was also drawn from the Community Transportation Resource Guide, *Community Transportation Reporter*, January 1989.

VEHICLE PURCHASE - CAPITAL ASSISTANCE PROGRAM FOR NONPROFIT AGENCIES TRANSPORTING THE ELDERLY AND HANDICAPPED

Purpose

This program provides funds to private, nonprofit organizations to assist in meeting capital expenses related to the special transportation needs of persons with disabilities and of the elderly.

Eligibility

A state agency, designated by the Governor, administers the program. Private, nonprofit organizations are eligible to apply for funds on a competitive basis.

Provisions

Federal grants are made to states based on the size of the population of persons with disabilities. The federal share of eligible capital costs may not exceed 80 percent and requires a 20 percent local match. Funds have been used to purchase buses, vans, or other paratransit vehicles; radios and communication equipment; vehicle rehabilitation; spare parts; initial installation costs; and vehicle procurement testing, inspection and acceptance costs.

RURAL AND SMALL COMMUNITY TRANSIT GRANTS: - FORMULA GRANT PROGRAM FOR NON-URBAN AREAS

Purpose

This program assists local transportation systems serving the general public in non-urban areas, with capital, and operating and administrative expenses. Federal assistance to states is provided for projects which enhance the access of people in non-urban areas to health care, shopping, education, employment, public services and recreation.

Eligibility

Funds are available to state agencies, local public bodies, nonprofit organizations, and operators of public transportation services for transportation projects in rural areas of less than 50,000 population. States receive an allotment of federal funds using a formula based on population. Funds pass through state agencies to local transportation systems including those run by private, non-profit organizations. Transportation must be targeted to the general public and may include transportation of non-urban residents to urban areas.

Provisions

The federal share for capital projects is 80% with a 20% match. However, accessibility projects for persons with disabilities can be funded up to 95% by federal dollars. Up to 15% of the total state allocation may be used for administration, planning, and technical assistance at 100% federal share. The federal share for net operating costs of transportation projects must have a 50% local match.

URBAN MASS TRANSIT GRANTS: - FORMULA GRANT PROGRAM FOR SMALL URBANIZED AREAS

Purpose

This program provides federal assistance for planning, capital and operation expenses of public transportation in small urbanized areas.

Eligibility

Each state governor (or designee) receives the federal funds. Funds are to be used for urbanized areas under 200,000 in population.

Provisions

Federal funds are allocated according to a formula based on overall population in small urbanized areas. Federal funds used for planning and/or capital assistance must be matched with 20 percent of local funds. However, accessibility projects for the elderly and for persons with disabilities can be funded up to as much as 95% by federal funds. The federal match for operating assistance is 50%.

HOUSING SUPPORTS

This section provides information on several funding streams that pertain to different types of housing supports. Section 202, low-income housing tax credits, and the Stewart B. Mckinney Homeless Act provide funds for the acquisition and/or development of housing units for persons (usually adults) with disabilities. Section 8 rental assistance and the Farmers Home Ownership loans provides housing opportunities for either adults with disabilities or low-income families (with or without a member with disabilities). The description of housing modifications discusses several funding streams that can be used to modify existing units in which adults or children with disabilities live. A description is also included of the recent fair housing amendments. Although the new provisions do not create funding opportunities for housing, they are included in the guide because they represent significant new changes in housing policies and civil rights pertaining to persons with disabilities.

Assistance with this section was provided by: Roberta Youmans, National Housing Law Project, 122 C ST. NW Suite 220, Washington DC 20001; Bonnie Milstein, Mental Health Law Project, 2021 L Street NW, Washington, DC 20036; and, G. William Mitchell, Housing Technical Assistance Project, Association for Retarded Citizens, 1522 K Street NW, Washington, DC 20005. For more information readers are advised to consult with them. A comprehensive description of housing resources for persons with disabilities is also available in: *Financing Housing for People with Disabilities*, by the Housing Technical Assistance Project, Association for Retarded Citizens, 1989.

LOW INCOME HOUSING TAX CREDITS

Purpose

The purpose of this program is to stimulate development, acquisition and/or rehabilitation of units of housing for low income individuals. Investors and owners of a property that meets low income specifications can receive a dollar for dollar reduction of their tax liability based on the cost of development and the number of qualified units for each of ten years. Units must comply with all requirements for a fifteen-year period.

Eligibility

"(The housing) project must have a minimum of either 20 percent of its units occupied by low income households with incomes under 50 percent of the area median income, or 40 percent of its units occupied by low income households with incomes under 60 percent of the area median income. Income limits are adjusted for various household sizes, and in certain unusually high or low housing cost areas" (Guggenheim, 1989, p.3). Rents that may be charged families in units on which a credit is claimed may not exceed 30 percent of the applicable qualifying income.

Group homes for persons with mental retardation or handicaps are eligible for tax credits so long as a separate landlord-tenant relationship with each individual is established. "Each unrelated individual can be considered as a one person household for purposes of maximum income and maximum rent determinations ..." (Guggenheim, 1989, p. 16). Housing cooperatives which are owned and controlled by the members who are the residents of the projects are also eligible to obtain and use tax credits. In addition, the provision to tenants of services other than housing will not prevent the property from qualifying for tax credits.

Provisions

Each state is given a dollar cap, based on population, representing the total number of dollars in tax credits that can be claimed for that state. Non-profit organizations are allocated a minimum of 10 percent of total credits in each state each year. States can directly allocate to specific projects or this function can be

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This description was largely drawn from Guggenheim, J., (1989). *Tax credits for low income housing*. Washington DC: Simon Publ. Readers are advised to consult this document for a complete analysis of this program.

shared by local agencies. In most cases, tax credits are allocated by the State Housing Finance Agency.

"Low income housing benefits from the tax credit primarily when the owners of a project, either profit-motivated or non-profit, 'sell' the tax credits to limited partner investors who contribute equity to the development in exchange for the use of the tax credits, and other economic benefits. These equity contributions, which can be substantial under this program, reduce the amount of other financing needed to acquire or develop the project. Or they could be used to add an income stream during the years of the project's operation, and thereby reduce the amount of rent the tenants have to pay for the project to operate successfully" (Guggenheim, p.4). In many cases, additional subsidies may be needed to facilitate the development of these units.

The amount of the tax credit is based on eligible cost elements (e.g., rehabilitation expenditures) and the percentage of the units that qualify as low-income, which is multiplied by a certain percentage. Guggenheim (1989) provides an example where a 100 unit building with total development costs of $3,850,000, which is 80% occupied by qualified low income tenants, yielded an annual tax credit of $172,400. There are limits on the number of tax credits that can be used by any individual and the legislation "virtually eliminates the use of tax crdits (by persons) at very high income limits" (p.39).

Proposed Revisions

The authorization for the Low Income Tax Credit expires on December 31, 1989. Legislation is pending in both the House and Senate to extend and modify its provisions.

DIRECT LOANS FOR HOUSING FOR THE ELDERLY OR HANDICAPPED (SECTION 202)

Purpose

This program provides federal low interest loans for new development, acquisition of existing housing or moderate rehabilitation for housing units for persons with handicaps and for the elderly and their respective families.

Eligibility

Direct loans for housing are available to private, incorporated, non-profit sponsors of housing developments on a competitive basis. Applications for projects in areas which previously have been underfunded relative to their needs will receive priority. The availability of funds is announced in the Federal Register. Adults with chronic mental illness, developmental disabilities or physical handicaps and their families or personal attendant may live in Section 202 housing. Generally, persons with incomes less than 50 percent of the median income for the locality are eligible.

Section 202 funds are usually used to fund group homes or apartment clusters for persons with disabilities. Structures funded with these loans may include housing facilities and cafeterias or dining halls, community rooms or buildings, or other essential service facilities. A maximum of 25% of the units in a project may be efficiency units subject to a HUD determination that such units are appropriate for the elderly or for persons with handicaps in the area. "Group homes funded with Section 202 funds may accommodate up to 15 persons with disabilities. Independent living complexes (ILCs) may be designed to serve persons with physical or developmental disabilities and their families in projects of not more than 24 units on one site" (Housing Technical Assistance Project, 1989). Projects may vary in layout and design but must be in compliance with the policies of modest design and cost containment.

Provisions

Forty year mortgages are made to eligible sponsors to finance rental or cooperative housing. The interest rate is determined annually. Due to recent legislative efforts, 25% of the national allocation for Section 202 funds is earmarked specifically for housing for individuals with handicaps and their families. Moreover, at least 10% of all Section 202 units developed for the elderly and all common areas must be wheel chair accessible and those units are given preference to adults with handicaps. Of the 25% allocation for persons with handicaps, priority must be given to projects for homeless persons with mental illness.

Residents of Section 202 developments pay only thirty percent of their adjusted income for rent and utilities thanks to the accompanying Section 8 rent subsidy. Until recently, Section 8 funds were made available for 100 percent of the Section 202 units to meet mortgage payments. However, this financing mechanism placed developers of housing for the handicapped at a disadvantage when competing against developers of housing for the elderly. To facilitate housing development for persons with handicaps recent amendments to HUD regulations replace the Section 8 rental subsidy with a new subsidy for persons with disabilities that is based on a different method for calculating development costs.

Project development with Section 202 funds is a time consuming and complex procedure (many projects can take up to two years before completion) which tends to favor experienced non-profit providers. Providers are expected to shoulder the burden of some front end financing costs and a small part of the loan. Owners must contribute one-half of one percent of the total HUD-approved mortgage amount. Sponsors may elect to pay for excess amenities that would not be permitted under the Department's cost containment guidelines.

SECTION 8 EXISTING HOUSING CERTIFICATE AND VOUCHER PROGRAM

Purpose

These programs provide subsidies to very low-income persons and their families to assist in paying rent in private rental housing.

Eligibility

Families with incomes that do not exceed 50 percent of the median income for the area they live in are eligible to participate in the program. The housing unit that the family selects to live in must meet HUD standards of sanitation and safety, and the rent must fall within the "Fair Market Rent" for the area as determined by HUD.

Each regional HUD office is allocated a portion of the total Section 8 certificates based on population. Public Housing Authorities and other organizations (e.g. state housing finance agencies) apply to the local HUD office for a share of the funds. Contracts with these authorities are awarded on a competitive basis for five years with renewals expected. Authorities submit requests based on documented housing needs for eligible families. Once awarded, the local housing authority processes applications for Section 8 certificates. There are long waiting lists at most Public Housing Authorities for certificates of participation. Only a small portion of those who are eligible actually receive certificates. Approximately 20% of existing Section 8 certificates turn over each year (Allard & Carling, 1986, p.71).

Congress established three preferences for allocation of certificates. Presently, preference is given to persons who are living in substandard housing, who are involuntarily displaced from housing because of federal action, and persons who pay more than 50% of their income on rent. Local housing authorities can establish a local preference for up to 10% of their certificates for certain populations. This can include a preference for persons with disabilities.

Provisions

Tenants in the Section 8 Existing program pay the highest of (1) 30 percent of their adjusted gross income; (2) 10 percent of gross income; or (3) the housing portion of a welfare grant. This includes an adjustment for utilities. The housing authority pays the difference between this amount and the Fair Market Rent to the landlord on a monthly basis. Tenants in the voucher programs, however, may pay more or less than 30 percent of their income because the subsidy is a fixed amount, and they may obtain housing at higher than the fair market rent.

All eligible families are placed on a single waiting list, with families that meet the "preference" criteria placed on top. Families are offered certificates or vouchers as they become available. A family may decline the voucher and wait for the next certificate (or vice verse) if they so choose. Once awarded a certificate or voucher the family is given up to a total of 120 days to find suitable housing.

Section 8 programs allow participating families to choose where they live (provided that the housing meet HUD safety and sanitary standards). Almost any type of housing, including group residences and single room occupancy may be eligible. The certificates are tied to individuals and not to the dwelling unit. However, while changes of residence within the boundaries of a particular housing authority contract are easily accommodated, a move out of the area usually involves the loss of a certificate. Once a certificate is awarded, the individual continues to receive the subsidy unless and until an increase in their income no longer makes them eligible. Tenant's income is reassesed for eligibility annually and subsidies are adjusted accordingly.

Housing authorities may reserve up to fifteen percent of their Section 8 certificates for project-based use. This provision was included in the 1987 Housing Act to facilitate the development of or rehabilitation of affordable housing. These certificates may be used in conjunction with the Low Income Housing Tax Credit and other programs. Low income housing development projects that obtain financial backing through assurances of Section 8 certificates from a housing authority can be specifically targeted to persons with disabilities, or any other population, provided they meet the income guidelines of the Section 8 existing housing certificate program.

The Section 8 Moderate Rehabilitation program provides a higher rent subsidy to landlords who undertake minor repairs to their units. These units once they are repaired must remain available to Section 8 eligible tenants for fifteen years. Housing authorities compete for funding for these units and in the last several years Congress has provided very little funding for the program. The Stewart B. McKinney Act authorized a special allocation of Section 8 Moderate Rehabilitation funds for Single Room Occupancy hotels (see following).

Community Housing and Services – PHA, Colorado

An innovative use of Section 8 certificates for persons with disabilities is made by the Colorado State Department of Institutions. This department is responsible for the delivery of services to persons with mental illness and developmental disabilities, and to juvenile offenders. "In 1977 the department formed a housing authority, Community Housing and Services (CHS), to provide community-based housing alternatives for its disabled population. This is the only statewide public housing authority administered through a human service agency. This program began with 80 Section 8 existing certificates provided through the Department of Housing and Urban Development, and an idealistic approach to assisting the most independent clients with subsidized housing. During the past 10 years, the program has grown to almost 1,000 Section 8 certificates and vouchers" (Palmer, 1987).

This program has been able to target 1,000 certificates (cumulatively) to consumers of the Department's services resulting in the placement of many high functioning persons with disabilities in their own housing. CHS works with many other agencies inside and outside of the Department of Institutions to provide the additional support services necessary. Landlords are persuaded to rent to these individuals in part by HUD's guarantee of damage and vacancy payments. "In addition, CHS establishes policy, provides technical assistance, holds informal hearings and often mediates problems between tenant, landlord and community center," (Palmer, 1987).

The use of Section 8 certificates has also assisted the efforts of Centennial Services of Weld County Colorado, a model supported living program for persons with disabilities. This program situates one or two consumers in rental housing where staff and other supports or added or reduced as needed to facilitate community living. The individual does not "graduate" to a new program as their skills increase, rather the housing is considered to be their permanent home. This approach also leaves facility maintenance in the hands of landlords rather than with the service agency (Model residential program meets individual needs, November, 1987).

8

FARMERS HOME ADMINISTRATION - HOME OWNERSHIP LOANS

Purpose

This program provides assistance to low-income families to purchase, build, or rehabilitate single family homes on individual tracts or subdivisions in rural areas in the form of insured or guaranteed loans. This discussion will focus or insured loans.

Eligibility

Applicants must meet the following conditions:

- Be presently without decent, safe and sanitary housing;
- Have low or moderate income;
- Have good credit and sufficient income to pay for living expenses, property taxes, insurance and upkeep, and the minimum mortgage payment required (see below);
- Be able to pay certain up-front costs (e.g., closing, house inspection, credit report); and
- Be otherwise unable to secure a mortgage from a private lending facility.

The home must be on at least a one-quarter to one-half acre lot depending on the utilities available and in rural areas with a population of 10,000 or less or in towns or cities with population under 20,000.

Provisions

Loans are made by the Farmers Home Administration (FmHA) at a market rate of interest and subsidized for low income families through the interest credit program. Interest credit enables the borrowing rate to be as low as 1% but it varies according to borrower income and the amount of the loan. When the borrower's income improves, he/she is required to refinance the loan through a commercial lender. Borrowers who have received an interest credit since October 1, 1979 are subject to "recapture" of part of that assistance when they resell.

This program is a potential but as of yet underutilized housing resource for individuals or families with a member with disabilities. Although targeted to low-income families and individuals, the financial requirements to meet ongoing expenses are often too high for individuals with disabilities. In some situations loans can be co-signed by other parties to facilitate acquisition.

A second program of FmHA is the Rural Rental Housing Program. This program authorizes FmHA to make up to 50 year market rate mortgage loans to private, public and nonprofit groups or individuals in order to provide rental or cooperative housing for low and moderate income families and individuals including persons with handicaps.

By statute, Section 515 housing is available to persons of any income level. In 1983, Congress made an attempt to target more of the assistance to the poor. Currently no more than 25 percent of all Section 515 units which were available for occupancy prior to November 30, 1983 may be rented to families with incomes greater than 50 percent of the area median. No more than five percent of all post-1983 may be rented to families with incomes greater than 50 percent of the area median. No more than five percent of all post-1983 units may be rented to those of non-very low income. Many Section 515 projects have additional rental subsidies attached to render the units more affordable. Tenants pay the highest of 30 percent of their adjusted gross income; 10 percent of gross; or the welfare allowance, as in the HUD program.

STEWART B. MCKINNEY HOMELESS ASSISTANCE ACT

Purpose

This program enacted numerous new programs and changes to existing programs to address the needs of homeless people by providing for emergency shelter, food, health care, mental health care, housing, educational programs, job training, and other community and planning services. Homeless persons are defined as being: 1) without a regular adequate nighttime residence; 2) living in a shelter; 3) living in an institution (other then a prison); 4) living in a place not ordinarily used as a sleeping accommodation for human beings (National Criteria for the Homeless, 1988). Provisions of the McKinney Act that are specifically relevant to persons with disabilities are reviewed here.

Section 8 Assistance for Single Room Occupancy

These grants are awarded on a competitive basis to local housing authorities who demonstrate a need for the assistance and the ability to undertake and carry out the program. Funds are used to finance the rehabilitation of SRO units for occupancy by the homeless. Units financed with this assistance shall remain available for at least ten years. Residents must meet the income criteria described earlier under the Section 8 program.

Permanent Housing for the Handicapped

The Housing Technical Assistance Project provides this description of the program:

> (This program) provides federal matching funds for the acquisition and rehabilitation of a supportive living home for up to eight individuals with disabilities or a building with up to eight housing units for persons with disabilities and their families who are either homeless or at risk of becoming homeless... The Permanent Housing Program targets people with disabilities with priority given to persons with mental illness... Persons with disabilities and their families who are either homeless, at risk of becoming homeless, or who have been residents of transitional housing under the Transitional Housing Program are eligible to be served under this program. (1989)

Public housing authorities or other non-profit housing sponsors may apply for the funds. They are required to operate the home and provide support services for the residents. Grants include funds of up to 50% (or $200,000) for the cost of acquisition and/or rehabilitation of existing property and for operating costs (including cost of support services) for up to 50% in the first year and 25% in the second year. States must match the other 50% of the costs.

Community Mental Health Services Demonstration Project

The National Governor's Association (1989) provides this discussion:

> This demonstration project provides discretionary grants for community-based mental health services to the homeless or those at risk of becoming homeless. The program is intended to fund up to twelve comprehensive, two-year community-based demonstration projects for homeless adults with severe, long-term mental illness and up to four grants for two year innovative demonstration projects serving emotionally disturbed children and adolescents. Services can include outreach, case management, treatment and rehabilitation, transitional housing, and staff training. (p. 15)

Other programs that may assist persons with disabilities include:

1) The Emergency Food and Shelter Program which provides rental and utility assistance on a one-time basis;

2) The Emergency Shelter Grants Program which provides matching grants to state and local governments for the development of shelters;

3) The Transitional Housing Program which provides advances, operating subsidies and technical assistance to nonprofit organizations.

HOUSING MODIFICATIONS

Housing modifications are alterations to existing environments that ease or make possible the residence of a person with handicaps. The type of modification necessary depends on the disability of the individual. Typical modifications include: widened doorways, ramps, lowered sinks and counters, adapted door handles, foot manipulated faucets, lighted phone and door signals, and grab bars. Modifications can be permanent or temporary (Barrier Free Environments, 1987). The recent Fair Housing Amendments Act of 1988 strengthens the rights of families or individuals to modify their rental units to meet their needs (see following).

There are no funding streams tied specifically or exclusively to housing modifications. However, a few funding streams have been successfully used by some states to support modifications. A survey of how states are funding housing modification programs was conducted by the Adaptive Environments Center (1989). The survey includes recommendations for implementing state funded housing adaptation programs as well as improved data collection to determine needs. The following funding streams were identified in the course of this study.

Medicaid waiver

The Medicaid waiver is described in the first section of this manual. Housing modifications are a specific service allowed under the waiver as long as they are shown to be a cost effective measure that reduces the need for a more restrictive or more costly setting. Waivers can be written to support as small or as large a population as desired and they can be designed for a population with specific disabilities or needs. The Adaptive Environments survey identified eight states that were using medicaid home and community-based waivers (including waivers for the elderly, and for persons with physical and developmental disabilities) to support home modifications for the waiver eligible population. (These states include: Idaho, Kentucky, Oregon, New York, Ohio, Pennsylvania, Colorado, and Rhode Island.)

Community Development Block Grants (CDBG)

According to the U.S. Dep't. of Housing and Urban Development (1988) this program:

Assistance with this section was provided by Elaine Ostroff, Adaptive Environments, 621 Huntington Avenue, Boston MA 02115.

> . . . provides annual grants on a formula basis to entitled communities to carry out a wide range of community development activities directed toward neighborhood revitalization, economic development, and improved community facilities and services. Entitlement communities develop their own programs and funding priorities and consult with local residents before making final decisions. All CDBG activities must benefit low- and moderate-income persons.

In the Adaptive Environments survey, states also reported using federal monies through Vocational Rehabilitation, Maternal and Child Health (MCH) Block Grants as well as general state funds to support home modification programs through state family support programs. Another financial source that has been identified are low interest loan programs through state housing finance agencies. Also noteworthy is the Farmers Home Administration, Section 504 program. "This program provides low-income rural home owners with up to $7,500 per unit in the form of grants and/or low interest loans for general repairs. Adaptations for accessibility are specifically designated as an eligible expense," (Housing Technical Assistance Project, 1989, p.20). One state that uses Maternal and Child Health funds is Massachusetts -- a profile of that program follows.

Massachusetts Adaptive Housing Program

The Massachusetts Department of Public Health has been providing home adaptations for children since 1984, through its Bureau of Parent, Child and Adolescent Health. The objectives of the program are to enable children to become more independent in their homes and to facilitate their mobility.

Families with mobility impaired children from birth to age 18 are eligible. They do not have to be clients of the agency. There are some income limitations on families, some of whom must contribute to the costs.

Families can receive either technical assistance, which provides them with a plan for their needs or planning, design and construction services provided through a private nonprofit contracted with the Department to administer the program. Ramps and lifts are the most frequently needed adaptations, with bathroom modifications the next most needed response. Other adaptations have included widened doorways, threshold removals, stair railings, and environmental control units.

Department of Public Health regional staff administer an initial prescreening assessment which identifies the child's environmental needs. Department and contractor staff work as a team with the family to determine the most practical solution, with the family having the final say on the selected design. The contractor prepares the working drawings and hires the subcontractor who will do the actual modification. The Department administers final evaluations. Evaluations showed increased independent access and egress for the child and reduced physical strain on the family.

Initially begun with funding from the Federal Emergency Jobs Bill, the program is now an integral part of the agency's program and budget. The annual budget has been at $100,000 per year and the funding per family has averaged about $4,000. More than 100 families have been served since the program began with about 15 to 20 families served each year. Families do not receive the funding directly.

As the program enters its seventh year, the Department is looking at how to expand services to families in the midst of reduced state budgets. Over the current year, strategies will be planned to bring in corporate funding as well as to identify more cost efficient ways to deliver the services. There is some other funding for families who need home modifications through low interest loan programs and other limited sources. A listing of funding resources in Massachusetts for home modifications has been produced and is available to individual families and agencies. The Adaptive Housing Program has also facilitated inter-agency cooperation, through joint planning and cost sharing, especially with the Massachusetts Commission for the Blind.

FAIR HOUSING AMENDMENTS ACT

Purpose

Milstein, Pepper, & Rubenstein (1989) ascribe three purposes to the act: 1) to end segregation in the housing of people with disabilities, 2) to give people with disabilities the right to choose where they wish to live, and 3) to require reasonable accommodations to their needs in securing appropriate housing." In general, the Act serves to extend the same protections granted to minorities in the 1968 Fair Housing Act to persons with disabilities.

Eligibility

The act utilizes the definition of "handicap" that is employed by Section 504 of the Rehabilitation Act of 1973, namely "a physical or mental impairment which substantially limits one or more of such person's major life activities; has a record of such an impairment; or is regarded as having such an impairment." This is a broad definition that includes mental illness, physical disability, visual impairment and mental retardation along with other handicaps but that excludes persons who illegally use or are addicted to a controlled substance.

Provisions

In general the prohibitions of discriminatory housing protections described in the 1968 Fair Housing Act apply to persons with handicaps. The new Amendments however, clarify and amplify the protections for persons with handicaps. The major provisions of the act are described below:

- Prohibitions against special restrictive housing covenants or denials of housing service because of an individual's handicap (for example covenant restrictions to single families that have the effect of excluding living arrangements for persons with handicaps);

- Prohibitions against discrimination of the primary purchaser or lessee on the basis of handicap and/or because they have family members, roommates, or other associates who have disabilities;

Material drawn from Milstein, B., Pepper, B., & Rubenstein, L. (1989). *The Fair Housing Amendments Act of 1988.* Washington: The Mental Health Law Project

- Landlords may not refuse to make *reasonable accommodations* "in rules, policies practices or services, when such accommodations may be necessary to afford such person equal opportunity to use and enjoy a dwelling." For example, HUD regulations explain that a 'no pets' policy may not be enforced to exclude a prospective tenant who uses a guide dog, (Milstein et al. 1989).

- Certain land-use rules can be considered discriminatory if they likewise deprive persons with handicaps with equal opportunity to a dwelling. This may apply for example to rules: prohibiting occupancy by unrelated persons, that exclude living arrangements involving paid staff, or that have the effect of limiting the ability of such individuals to live in the residence of their choice in the community by limiting the numbers of persons or group facilities that can be established in a given area, especially when similar quotas are not placed on other persons or families living in the area. Similarly, requirements of special or conditional permits for group home providers are considered unlawful if such restrictions are placed only on persons with disabilities.

- Property owners are permitted to deny housing opportunities to persons with handicaps only when their tenancy would constitute a direct threat to the health and safety of other individuals or would result in substantial physical damage to the property of others. This can only be determined by procedures that the landlord would apply to any other tenant. Direct threat does not include for example, nicks in doorways caused by a wheelchair.

- New accessibility and adaptability requirements for new multifamily dwellings (excluding townhouses) with four or more housing units and elevators. Requirements include:

  * accessibility of public use and common use portions of the building;

  * all doorways are widened for accessibility;

  * accessible routes into and through the building;

  * environmental controls and switches in accessible locations;

  * reinforcements in bathroom walls to allow later installation of grab bars;

  * sufficient space in bathrooms and kitchens such that a wheelchair can be maneuvered about (this does not mean sufficient space for full turning radius).

In buildings with four or more units but no elevator, only the ground floor dwellings must contain these features.

- Tenants are permitted to "make reasonable modifications of existing premises ... if such modifications may be necessary to afford such person full enjoyment of the premises." For example, a landlord cannot prohibit modifications such as lighted door warnings or altered counters or doorways. Landlords may require that the tenant restore the premises to original condition upon vacancy; if the requirement is a reasonable one.

The Act also provides strong measures of enforcement. When a person with a disability feels he/she has been discriminated against by a landlord or seller, he/she may either file a complaint with HUD which triggers an investigation by the Fair Housing Office. The parties to a complaint may elect to have the complaint heard by an administrative law judge or in federal court under the auspices of the Department of Justice (Milstein et al., 1989). An aggrieved party also has the right to file his or her case directly in court without first filing a complaint with any administrative agency.

PART TWO: PUBLIC/PRIVATE OPTIONS

The second section of this manual includes descriptions of strategies that employ public and private partnerships to support adequate health and home care for children with chronic illness or disabilities. All of the strategies involve state government and private insurance collaboration. Nearly all have been adopted in at least one state.

The following description of options were adapted from two publications by Harriet Fox of the Fox Health Policy Consultants. These two publications are:

> September 1984, ***A preliminary analysis of options to improve health insurance coverage for chronically ill and disabled children*** (Report); and
>
> July, 1987, ***Presentation on the policy implications of various catastrophic health expense program options for children*** (Presentation).

A discussion of these topics is also available in:

> Griss, G. (September 1988). Measuring the health insurance needs of persons with disabilities and persons with chronic illness. ***Access to Health Care***, *1*(1&2), 1-63. Berkeley CA: World Institute on Disability.

To obtain a comprehensive analysis of the options described here, readers are advised to consult these three documents. They are available from, respectively: Fox Health Policy Consultants, 1140 Connecticut Avenue, NW, Suite 1205, Washington, DC 20036 and the World Institute on Disability, 1720 Oregon Street, Suite 4, Berkeley CA 94703.

STATE "HIGH RISK" POOLS

Purpose

Risk pools are independent associations of all health care insurers in a given state who share the financial risks of offering individual comprehensive health insurance to persons considered to be uninsurable or poor risks because of pre-existing conditions (Fox 1984). "Through the pool arrangement, the risk of loss in covering this population is spread across all insurers so that each participating insurer's risk is reduced. The pool establishes the premium rate. Actual losses (or profits) are absorbed by and shared equitably among all members" (Fox 1987a, p. 8). States can subsidize potential losses of the pools through various mechanisms.

High risk pools effectively provide insurance to people who are otherwise unable to purchase it because of individual insurance company restrictions or because of inordinately high premiums. Premium rates for risk pool coverage are capped by state law and range from 125% to 400% of the average charged for an individual policy for a standard risk. The cost of premiums for risk pools generally excludes the participation of low-income people but prevents high medical expenses from impoverishing middle income people and can reduce the amount of uncompensated care. Some states subsidize the premiums for low-income families (Fox, 1987a). Presently mandated high-risk pools are available in 15 states (Intergovernmental Health Policy Program, George Washington University, personal communication).

Eligibility

Eligibility requirements vary by state. However, the state-mandated pools are usually "designed to serve people who have no access to an employee or other group health plan and whose only option is an individual health insurance policy. Applicants to the pool are generally required by law to prove that they attempted to secure individual coverage from at least two carriers but either were rejected for insurance or were offered coverage with restrictions additional to those in a standard policy. Such restrictions are defined as pre-existing limitation, substantially higher premiums, or restrictive riders" (Fox, 1984, p. 24).

Services offered

A minimum benefit package for a qualified plan is prescribed by legislation. "Pool coverage is comprehensive but it frequently fails to include adequate coverage for speech and occupational therapy or extended home care, except in lieu of a more costly hospitalization" (Fox, 1987a p.9). Also, lifetime maximum benefits may be exceptionally low and generally benefits may be less inclusive than regular individual policies (Fox, 1987a).

STATE-FINANCED CATASTROPHIC HEALTH INSURANCE

Purpose

Fox (1984) describes this option as follows:

> A state-financed catastrophic health expense program is one in which the state functions as the payor of last resort for persons who have incurred very substantial out-of-pocket expenses for medical care. It is intended primarily to benefit working families who have some financial resources but, because of inadequate health insurance, would be financially devastated by extensive medical bills that could result from a serious or prolonged illness. The program is designed to serve the uninsured as well as the underinsured who have exhausted their benefits. (p.27)

Financing for these programs comes from general state revenues (Fox 1987a).

Eligibility

Under state catastrophic health expense programs, families are usually required to incur substantial uninsured health care costs that remain their liability. Assistance is provided when out-of-pocket expenses exceed a certain dollar threshold or a certain percentage of family income. The amount of "the deductible" or the percent of income is commensurate with the family's liability and varies from program to program. Usually eligibility for the program is met by inpatient care episodes. This is because ambulatory care providers (such as nursing care at home) are usually unwilling or unable to bear the amount of uncompensated care required of the family for the family to become eligible for the program (Fox 1984).

Services covered

The services covered will depend on the program itself. Fox (1984) notes:

> Not all medical and health care expenses are permissible, however. Covered services are specified by statutes or by regulation. Generally, they include those services usually covered under a standard comprehensive health insurance policy: hospital and physician services plus some other services such as prescription drugs, medical equipment, and limited long term care. Speech therapy, physical therapy, and psychiatric care are not covered under every program. (p.29)

Although five states have enacted enabling legislation for catastrophic health expense programs, only three are currently in effect (in Alaska, Maine, and Rhode Island) (Fox 1984). [Recently, a similar program was enacted in New Jersey which specifically provides financial assistance to families who incur medical expenses that are a substantial percentage of their gross income due to the care of a child with chronic illness or disability.] State experience with this type of program has not been very positive. Data indicate that with low eligibility deductibles, a large portion of program benefits go to assist the uninsured poor in paying medical benefits that could not really be considered catastrophic rather than assisting the middle-class who were underinsured. However, setting the deductibles high places a considerable out-of-pocket financial burden on the low and moderate income families relative to their income while no such hardship is placed on higher income families (Fox 1987a). Fox notes:

> If, on the other hand, a percentage of a family's income -- even as high as 15% were used to trigger eligibility, then many more children from low- and moderate-income families would be able to participate -- but their out-of-pocket liability may not in any objective sense be considered catastrophic... In a family whose annual income is $12,000, for example, a child would become eligible for catastrophic coverage after incurring an $1,800 bill for a tonsillectomy which required only a one and a half day in a hospital. (Fox, 1987a, p.3)

To prevent this from happening, eligibility can also be tied to the duration of the illness and/or the projection of annual health care costs to help ensure that the program is reaching persons with catastrophic illness. "It seems that for a catastrophic health expense program to sustain political approval, the deductible, or family liability, has to be set high enough so that 1) uninsurance is not encouraged and 2) only those with truly catastrophic expenses are served" (Fox, 1987a, p.4).

STATE SUBSIDIES FOR PRIVATE HEALTH INSURANCE

Purpose

This option is targeted to low- and moderate-income families and has the advantage of reaching the vast majority of the uninsured. It involves the use of state subsidies toward the purchase of private health insurance coverage. This approach has been enacted in one state and is proposed in nine others (Fox 1987a).

Eligibility

Criteria for enrollment is determined by the state. Washington has a premium subsidy for individuals and families with incomes up to 200 percent of the federal poverty level (Fox 1987a).

Services offered

Eligible families can receive state vouchers to purchase health insurance. However, the private policy may be inadequate for the needs of children with chronic illness (e.g., because of a low lifetime maximum coverage, and/or by not insuring all services). Moreover, even with a voucher, adequate coverage for children with chronic illness may not be affordable. To counteract this, minimum benefits that must be purchased with the state voucher may be specified. Alternatively, an insurer may be selected by the state to offer a state qualified benefits package to all persons eligible for the subsidy.

Fox (1987a) notes:

> Forming a group would appear to be more cost-effective, given that the cost of individual coverage usually runs about 130 to 150 percent of the cost of a group policy. But, if the group plan approach were adopted it would be important for those concerned about financing the case of children with chronic medical conditions to assure that the specified state plan takes into account the range and intensity of specialty services needed by these children, as well as the preventive health examinations needed by the presumably "healthy" child population. If an appropriate plan were offered, chronically ill children would be able to obtain good coverage and it would be at a reasonable premium because costs would be spread across high- and low-risk populations. On the other hand, if a voucher system were used, children with chronic medical conditions probably would not be able to purchase affordable individual coverage at

all. In fact in the two states with a proposed voucher system, a high-risk pool is either in operation or under consideration by the legislature. (p. 15)

The high risk pool helps to insure adequate coverage at a reasonable price. Another drawback to this approach is that it does not address those persons who have existing private insurance that is inadequate.

STATE - MANDATED CATASTROPHIC HEALTH INSURANCE

Purpose

Under this option, all state insurance companies are required to offer catastrophic health insurance coverage. "Carriers would be expected to participate in an association or pool in which each would share in the gains and losses on an equitable, proportionate basis" (Fox, 1984, p. 30). Financing would come from subscriber premiums. This program has not currently been adopted by any state. It is a model act proposed by the National Association of Insurance Commissioners. Unlike state financed programs, private insurers would be the vehicle for making catastrophic coverage available (Fox 1984).

Eligibility

Eligibility for reimbursement of extensive medical bills would be dependent on the prior purchase of catastrophic health insurance. "Under the model act, applicants would not have to meet any specific eligibility criteria. Uninsured as well as insured persons could enroll" (Fox, 1984, p. 30). This program does not address families who are too poor to pay for any private insurance premiums. Therefore, the model act would also allow states to choose to grant their Medicaid programs the authority to purchase catastrophic health insurance for persons eligible under Medicaid. This provision may facilitate the reduction of Medicaid rolls (Fox, 1984).

Services offered

In the model legislation, benefits are based on allowable expenses that exceed a certain threshold per year. The family's liability would be determined by the extent of the insurance coverage. "The basic formula would be that all reasonable charges for the necessary care and treatment of any sickness or injury incurred during the year would be reimbursed if they exceeded $5,000 in the case of an individual, or $7,500 in the case of a family" (Fox, 1984, p.31). The proposal requires that the premium be reasonable in relation to the benefits provided, suggesting that high premiums are possible. No cap on the amount that the insureds could be charged is proposed (Fox, 1984).

MANDATED EMPLOYER-BASED COVERAGE

Purpose

In this model, "all employers with a specified number of employees would be federally required to provide a minimum package of benefits to employees working at least half-time" (Fox, 1987a). Since the great majority of uninsured children have an employed parent, this program can facilitate insurance coverage for children with disabilities. Federal legislation on this type of coverage will be introduced in 1989.

Eligibility

In general, all employees and their families of specified employers would be covered. In recent legislation in Massachusetts, all employees of businesses that have more than five employees are covered.

Services offered

The required benefits package is determined by the state and may or may not provide adequate coverage for children with chronic illness or disability.

Massachusetts Universal Health Security Act

This recent legislation provides for insurance for uninsured persons largely through an employer based program. After a four year phase-in, all employers of six or more full or permanent part time employees are required to contribute to a state health insurance pool from which their uninsured employees and their families can purchase health and managed care coverage by paying premiums based on a sliding fee scale. Employers who already purchase health insurance for their workers can deduct these expenditures, on a dollar-for-dollar basis, from their required contribution to the pool. Most employers who provide employee health insurance are not expected to have to contribute to the state pool. Employers with less than six employees are exempt from contributing to the coverage, however special tax incentives were written into the bill to encourage small employer participation. Small businesses are able to purchase insurance from the state pool at rates that would be comparable to groups of large employees. Massachusetts residents who are not covered by either small or large employers will be able to obtain affordable insurance through the state purchased group plans. These include part-time and seasonal employees, persons receiving unemployment insurance, and the self-employed. The legislation also allows adults with disabilities and/or parents of children with disabilities to purchase "wraparound" coverage from the state. This is health coverage that is comparable to the Medicaid benefits available for families with children with disabilities, thereby eliminating the disincentive to work because of threat of loss of Medicaid benefits.

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APPENDIX A:

LEGISLATIVE ACTS AND AUTHORIZATION FOR PROGRAMS

Abandoned Infants Assistance Act – Public Law 100-505.

Child and Adolescent Service System Program – Section 520A of the Public Health Service Amendments of 1987, P.L. 100-177.

Child Welfare Services – Title IV-B of the Social Security Act, as amended by the Adoption Assistance and Child Welfare Act of 1980, P.L. 96-272, 42 U.S.C. 620 et seq.

Crisis Nurseries and Respite – Children's Justice and Assistance Act, Title II, Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986, P.L. 99-401, 42 U.S.C. 5117, et seq.

Developmental Disabilities Act – Disabilities Assistance and Bill of Rights Act Amendments of 1987, P.L. 100-146.

Direct Loans for Housing for the Elderly and Handicapped – Section 202, Housing Act of 1959, 12 U.S.C. 1701 et seq.

Early Intervention Program for Infants and Toddlers – Public Law 99-457, Title I.

Education of All Handicapped Children Act – Public Law 94-142.

Fair Housing Amendments Act – P.L. 100-430

Farmers Home Administration -- Home Ownership Loans – Housing Act of 1949, P.L. 81-171.

Federal Preschool Program – Public Law 99-457, Title II.

Foster Care and Adoption Assistance – The Adoption Assistance and Child Welfare Act of 1980, P.L. 96-272, Title IV-E of the Social Security Act, 42 U.S.C. 670 et seq.

Head Start – Human Services Reauthorization Act of 1986, Title I, P.L. 99-425.

Low Income Housing Tax Credits – Section 252 of the Tax Reform Act of 1986, P.L. 99-514 as amended by the Technical and Miscellaneous Revenue Act of 1988, P.L. 100-647.

Maternal and Child Health Block Grants – Omnibus Reconciliation Act of 1981.

Medicaid: Medical Assistance Program – Title XIX, Social Security Act.

> ***Home and Community Based Waiver*** – Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, Section 2176.
>
> ***Model Waiver*** – Section 1915(c) of the Social Security Act
>
> ***Waiver Program for Border Babies*** – P.L. 100-360, Medicare Catastrophic Coverage Act of 1988.

Medicare – Social Security Amendments of 1965; Title XVII, Parts A&B, P.L. 89-97, Public Law Amendments; and U.S.C. 1395 et seq; Social Security Disability Amendments, P.L. 96-265; P.L. 97-248; and Section 1 of P.L. 98-21, 42 U.S.C. 1305.

Rural and Small Community Grants: Rural Transit Assistance Program – Section 18, Urban Mass Transportation Act of 1964, P.L. 88-365.

Section 8 Existing Housing Certificate and Voucher Program – Section 8(o), U.S. Housing Act of 1937, P.L. 93-383, 42 U.S.C. 1437f(o).

Social Security Block Grant – Social Security Act, Title XX; as amended by the Omnibus Budget Reconciliation Act P.L. 97-35.

Social Security Disability Insurance – Social Security Act of 1935; Public Law Amendments; and U.S.C. 420-425 Title II of the Social Security Act.

Supplemental Security Income – Title XVI of the Social Security Act.

Stewart B. McKinney Homeless Assistance Act – P.L. 100-77.

Technology Assistance Act – Technology Related Assistance For Individuals With Disabilities Act of 1988, P.L. 100-407.

Urban Mass Transit Acts: Formula Grant Program for Non-urban Areas – Section 18, Urban Mass Transportation Act of 1964, P.L. 88-365.

Vehicle Purchase: Capital Assistance Program for Nonprofit Agencies Transporting the Elderly and Handicapped – Section 16 (b)(2), Urban Mass Transportation Act of 1964, P.L. 88-365.

APPENDIX B:

FEDERAL PARTICIPATION RATE FOR MEDICAID PROGRAMS BY STATE

Federal Matching Rate for Medicaid Services by State (FY 1988)

State	Rate	State	Rate
ALABAMA	73.29	NEBRASKA	59.73
ALASKA	50.00	NEVADA	50.25
ARIZONA	62.12	NEW HAMPSHIRE	50.00
ARKANSAS	74.21	NEW JERSEY	50.00
CALIFORNIA	50.00	NEW MEXICO	71.52
COLORADO	50.00	NEW YORK	50.00
CONNECTICUT	50.00	NORTH CAROLINA	68.68
DELAWARE	51.90	NORTH DAKOTA	64.87
FLORIDA	55.39	OHIO	59.10
GEORGIA	63.84	OKLAHOMA	63.33
HAWAII	53.71	OREGON	62.11
IDAHO	70.47	PENNSYLVANIA	57.35
ILLINOIS	50.00	RHODE ISLAND	54.85
INDIANA	63.71	SOUTH CAROLINA	73.49
IOWA	62.75	SOUTH DAKOTA	70.43
KANSAS	55.20	TENNESSEE	70.64
KENTUCKY	72.27	TEXAS	56.91
LOUISIANA	68.26	UTAH	73.73
MAINE	67.08	VERMONT	66.23
MARYLAND	50.00	VIRGINIA	51.34
MASSACHUSETTS	50.00	WASHINGTON	53.21
MICHIGAN	56.48	WEST VIRGINIA	74.84
MINNESOTA	53.98	WISCONSIN	58.98
MISSISSIPPI	79.65	WYOMING	57.96
MISSOURI	59.27	D.C.	50.00
MONTANA	69.40		